

**PATTERNS OF CARING FOR OLDER PEOPLE:  
AN ETHNIC DIMENSION**

by

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## ABSTRACT

*Care in the community increasingly means care by the community, i.e. the family. The present focus on informal carers by policy makers reflects their importance to the success of community care legislation (NHS and Community Care Act, 1990; Carers (Recognition and Services) Act, 1995). Much of the published information on the impact of caring has neglected the circumstances of carers from minority ethnic groups. Hence, this research explores the caring situations and experiences of informal carers of older people from Gujarati, Punjabi and white indigenous communities.*

*Semi-structured interview schedules were used to elicit both quantitative and qualitative information from each of the three groups. Overall, the data confirmed some universal features of caring in that it is the family, and in particular women, who care for older people. However, the motivation for caring differed between the three cultural groups.*

*Findings also showed that many of the socio-demographic characteristics in the Gujarati and Punjabi groups were similar in that they tended to be co-resident, were younger and cared for a younger age group than white indigenous carers. However, a closer look at the data on the psychosocial aspects of caring revealed some distinct differences between the two South Asian groups. Gujarati and white indigenous carers reported higher levels of morale, significantly lower levels of stress and significantly higher perceived coping abilities than the Punjabi group of carers. This latter group reported using a proportionately lower number of active coping strategies and more avoidance coping techniques than Gujarati and white indigenous carers. Punjabi carers were also significantly less satisfied with any help received from formal and informal sources than the other two groups.*

*In light of these findings, which emphasize some distinct differences in caring circumstances, a number of recommendations are made for both policy makers and future research.*

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# CHAPTER ONE

## AN OVERVIEW OF THE THESIS

### 1.1 Introduction

This research investigates the circumstances and experiences of informal carers of older people from three different cultural groups in Northamptonshire. The driving force behind this thesis is that, despite a plethora of research on informal carers in general, there is little published information on carers from minority ethnic groups. Therefore, the study seeks to address this shortcoming by drawing distinctions between the experiences of minority ethnic carers and those from the white indigenous community. The nature of the study has required a detailed exploration into various aspects of community care. The aim is to seek conclusions relevant to community care in general with regard to different cultural groups and ethnically related psychosocial aspects of providing informal care in the community.

A complete survey of informal carers of older people relating to all minority ethnic and indigenous communities in Britain was not a viable option. Such a study would be enormous in scale and complicated to draw conclusions from. Instead, a more targeted approach examining informal carers from three different communities was carried out. The chosen samples were two groups of South Asian origin (Gujarati and Punjabi) and the white indigenous community domiciled in Northamptonshire. This approach provided an opportunity to gain a clear picture of ethnically related caring situations in a manner that a more diverse study might not. It is hoped that clear conclusions can help in the design of well conceived policies that can be of benefit to informal carers of all communities.

In sympathy with the structure of the thesis, this chapter shall examine first the demographic and policy background to the study (section 1.2). A more detailed introduction to the structure of the thesis is provided in section 1.3. Finally, the chapter concludes with a section on the terminology and abbreviations that have been used in this thesis (section 1.4). Clarification is important in an area where terminology changes constantly.

## **1.2 Background of the Thesis**

The experiences and circumstances of informal carers of older people from three different cultural backgrounds (Gujarati, Punjabi and white indigenous) are the subject of this thesis. Supporting older people in the community is one of the main objectives of the White Paper Caring for People (Cmnd. 849, 1989) and the NHS and Community Care Act, 1990.

The shift in emphasis towards caring by the community has changed the focus of care for older people from formal carers to informal carers. This involves an unequivocal assumption that informal carers accept this role. Informal carers' willingness to care is therefore of paramount importance if new legislative changes are to be sustained.

Although identified as a priority group in community care initiatives, older people and their carers do not form an homogeneous entity. Diversity includes gender, kinship, social class and, of particular concern here, ethnicity. Hitherto, policy makers and academics have expressed little concern in race or ethnic related issues. Consequently the importance of ethnicity in community care policy formulation has been neglected even though increasing numbers of cohorts of migrants to Britain are reaching a pensionable age (OPCS, 1991). There exists little information about the needs of minority ethnic communities at a time when Britain's ageing population is bringing into question the capacity of the community to

care for the predicted increase in the numbers of frail and older people ('Growing Older', Cmnd. 8173: 1981). In this context a number of service and policy initiatives have been taken to provide supportive assistance to enable informal carers to continue in their caregiving roles. Studies have documented the inaccessible and unsuitable nature of service provision to people from ethnic minority groups and their carers in their various heterogeneous communities (Norman, 1985; Fenton, 1987; Bowling, 1990; McCalman, 1990; Walker and Ahmad, 1994).

A burgeoning body of research has also substantiated the significant levels of care given by individual men and women and highlighted the high levels of stress which they may experience (e.g. Gilleard *et al.*, 1984; Russell *et al.*, 1989; Jones and Peters, 1992; Milne *et al.*, 1993). Although there is substantial literature exploring the nature of care and carers' experiences, there is no available research on the different styles of coping used by carers in different cultural groups. If the NHS and Community Care Act, 1990, is to successfully deliver fair and equitable services for all, the question of caring and ethnicity cannot be ignored, and is therefore of special interest.

In accordance with these current considerations and as a response to gaps in our knowledge this research aims to address these shortcomings on three fronts. Firstly, the study will consider the issues surrounding the introduction of the NHS and Community Care Act, 1990, on the circumstances of informal carers, and whether its implementation is being realised as effective, accessible, suitable and equitable to all users of community care in a multi-racial and multi-cultural society. Secondly, through analysing and comparing a range of social and psychological factors, this study aims to provide further knowledge of the experience of caring, its stresses and coping strategies used by different cultural groups.

Thirdly, research findings will aim to establish similarities and differences in carers by determining some particular needs of different carer groups. Suggestions arising from this study will indicate how best those different groups can obtain relevant information and help. Furthermore, research recommendations will also be proposed to enable community care agencies to design and provide user-sensitive services.

### **1.3 Structure of the Thesis**

The overall thesis will be divided into three main parts. The study undertakes a large literature review, which is presented thematically in Chapters 2, 3 and 4. Chapter 5 relates to the methodology and the nature of the three different cultural groups taking part in this research. The results are presented in Chapters 6, 7 and 8 with Chapters 9 and 10 concluding the study and making recommendations for the future.

Chapter 2 reviews the issues surrounding the present community care initiative-i.e. the NHS and Community Care Act, 1990, -which has to date been implemented for almost six years (April, 1993). It reviews the history and philosophy of community care, thereby introducing some of the concerns relating to the expected increase in the numbers of frail and very old people requiring support in the community. Following this, the implications of the policy objective of 'care by the community' are discussed. This section also explores whether government policy is translated into actual support available for carers (e.g. Carers (Recognition and Services) Act, 1995). The chapter then places the emphasis on the role of carers who are expected to provide the bulk of the care required. Hence, this part also identifies the importance of formal service provision in enabling carers to continue in their caregiving role before finally looking at some of the characteristics of informal carers and the nature of informal caregiving.

Chapter 3 examines specific issues relating to minority ethnic groups raised by the NHS and Community Care Act, 1990. Only recently, has the potential significance of ethnicity in policy formulation in community care been recognised. The chapter will therefore explore pertinent issues regarding migration, identity, social organisation and health in South Asian groups and how these may impact on caregiving. Hence, it also examines formal service provisions available to people from a minority ethnic background and explores, in particular, whether services are considered accessible, adequate and appropriate to their needs. Finally, the chapter explores how the informal care situation may be different for carers from minority ethnic groups.

Chapter 4 reviews the literature on the nature and effects of informal caring. The NHS and Community Care Act, 1990, places an emphasis on the continued support to older people by informal carers; however a large body of evidence has reported that carers may suffer stress as a result of caring. It therefore becomes important, if only for pragmatic reasons, to explore factors that ameliorate stress levels or which help carers to cope. Hence this chapter not only details the sources of stress, but also examines the importance of individual coping mechanisms and formal and informal social support systems and their implication for community care initiatives.

Chapter 5 outlines the methodology of the study by stating the aims and objectives of the project. Following a discussion of the hypotheses the chapter details the design of the project. It also describes the samples chosen for comparison, i.e., Gujarati, Punjabi and white indigenous communities. Detailed information regarding the data collection process is outlined here along with the rationale behind the use of Gujarati and Punjabi speaking interviewers, as well as the measures used for the collection of quantitative and qualitative

information in this study. The chapter concludes by appraising the methodological limitations of the study.

Chapter 6 constitutes the first chapter of findings in a series of three. It takes a detailed look at the social and demographic characteristics of carers in the different cultural groups. It identifies informal carers in terms of their distribution by the Community Health Council (Northamptonshire-North and Northamptonshire-South) as well as their age, gender, socio-economic status, language and religious affiliation. It then goes on to examine the social and demographic factors pertaining to the older person in need of care and also explores the relationship of the older person to their carer. By looking at the particular features of both the carers participating in this study and the older person they are caring for, the chapter is able to discern similarities and differences as well as any interaction of factors between the three different cultural groups which are relevant for subsequent analyses.

The second results chapter (Chapter 7) combines both quantitative and qualitative material gathered from the interview schedule. The chapter explores the psychosocial impact of caring on carers of older people by investigating hypotheses 1 and 2 concerning levels and experience of perceived morale and stress, outlined in Chapter 5. By using relevant analyses, it looks at similarities and differences between the three cultural groups and in comparison to other studies. The chapter begins by exploring carers' motivation to care and some positive aspects of caring that can exist alongside the experience of stress. It then goes on to look at the level of care provided by the carers. This is followed by an assessment of carers' perceived morale. Succeeding this, the perceived level of stress in carers is appraised. Finally, some possible sources of stress are outlined. This chapter thereby explores both psychosocial and cultural differences in the nature and experience of caring.

Chapter 8 is the final results chapter of the thesis. It follows the same format as the previous results chapter in that both quantitative and qualitative material is used to give strength to the findings. Analyses of similarities and differences between the three cultural groups in terms of coping with their caregiving responsibilities are made. Thus, the chapter examines hypothesis 3 and begins by focusing on how carers perceive their different coping abilities and levels. Following this, carers' internal coping mechanisms are assessed. The chapter concludes by looking at external coping strategies employed by the carers from the different cultural groups participating in this study. Hence, the chapter attempts to address the gap in knowledge concerning mediating factors in the experience of stress in carers from different cultural groups.

Chapter 9 appraises the main and associated findings of the study as collated from the preceding three results chapters. It focuses on universal findings in addition to some specific distinctions such as ethnicity and culture in caring for older people, which are unique to this research. The particular concerns of the carers from the three cultural groups researched in relation to community care objectives are also discussed. The chapter therefore considers the cultural differences between the carers, which lead to some general conclusions regarding the situation and experience of carers from different ethnic backgrounds.

Chapter 10 concludes the thesis. The chapter is a synthesis of, not only the needs of carers in general, but the needs of different groups of carers as apparent in the research. It also endeavours to make suggestions, which may be used to enable both carers themselves as well as to assist formal health and social agencies to provide a more user-sensitive service. Following this, some recommendations for future research are made. Finally, some of the main findings, unique to this research are reiterated, which brings this thesis to a conclusion.

#### **1.4 Terminology and Abbreviations**

Terms used to describe groups in the community are constantly changing and therefore remain a sensitive issue in that they reflect disablist or racist tendencies in society. It is therefore useful at this point to explain some of the terms, which will be regularly encountered throughout this work.

The research refers to 'informal carers' though often just the word 'carers' will be found. Both terms will refer to informal care and are used to distinguish caring roles from those of formal care provided on an organised and paid basis. Informal care by contrast is provided on an unpaid basis normally occurring within a family or friendship context. Where formal care is indicated this will be specified.

Main informal carers are defined as those who are largely responsible for looking after or providing some regular service for older people in their own household or elsewhere (e.g. the General Household Survey, 1985).

The term older people is preferred to the use of 'the elderly' or elderly people which may be associated with the perception of older people as being dependent and in need of care. Being older is not an indication of need in itself; however disability and illness increase with age and therefore more older people require more support, more resources and more people to care for them.

The terms ethnicity and culture have been used interchangeably in this thesis. Although it is accepted that both have a distinct meaning (Aranda and Knight, 1997), both also refer to a particular social and cultural heritage that is passed on through different generations.

In this study older people refers to individuals 55 years of age and above. This particular cut-off point in age was considered following the recognition that South Asian people may have different perceptions of old age (Mays, 1983) and that minority ethnic people may age earlier than the indigenous white population (McCalman, 1990). The guiding principle in the choice of terminology used to describe members of different ethnic groups is the desire to avoid inadvertent offence.

Minority ethnic groups will refer to those identified as being non-white people not previously indigenous to Britain. Indigenous white people are defined as those people whose families are native to Britain. Although the term 'Asian' is often found under the umbrella term 'black', mainly to describe minority groups' common experience of discrimination and inequality, many Asian people object to the word black as it obfuscates the diversity of ethnic groups (Atkin and Rollings, 1993). This research will often employ the use of the term 'Asian' for those of South Asian descent and will largely focus on people originally from the Indian subcontinent who now live in Britain. The main distinction in this research will be those whose first language is Gujarati or Punjabi.

In addition to the terms described above, this thesis relies on texts with common acronyms. For a better understanding, and as a quick reference guide, abbreviations regularly used in the text are detailed.

<u>Abbreviation</u>	<u>Term in Full</u>
CSO	Central Statistics Office
DHSS	Department of Health and Social Security
EOC	Equal Opportunities Commission
GHS	General Household Survey
OPCS	Office of Population Censuses and Surveys

This opening chapter has provided not only a basis for research, but has also served to give a necessary overview of the thesis. It has further introduced some of the more complex aspects surrounding caring, and the ethnic perspective within community care provision and delivery, which this study has entailed. The main body of the research now begins with the ensuing chapter (Chapter 2) which focuses on present community care initiatives and their impact on informal carers of older people.

## CHAPTER TWO

### THE SIGNIFICANCE OF CARERS IN COMMUNITY CARE POLICY

#### 2.1 Introduction

Informal carers of older people and their importance in the community care arena form the subject of this chapter. It is widely acknowledged that the majority of informal care has for some time, and continues to be, provided mainly by the family (Qureshi and Walker, 1989; Parker, G., 1990; Parker, R., 1990; Nocon and Qureshi, 1996). Nonetheless, since the early 1980s there has been a growing concern about the increasing numbers of older people, especially the very old, who may need some form of health or social care (Glendinning, 1992; Tester, 1996). This has meant that caregiving among families has gained increasing visibility over the past decade. Recent policy initiatives in care provision have therefore been necessary to take these developments into account. Consequently, care for older people, especially for very frail older people, has become a main social policy issue where informal carers form a group of major importance in the provision of community care.

The chapter is divided into three main sections. The first part briefly looks at the historical development of the shift in emphasis on carers (section 2.2). It then explores some of the reasoning behind the change of focus from formal to mainly informal care by citing some influential policy documents, the culmination of which have resulted in the NHS and Community Care Act, 1990, and the Carers (Recognition and Services) Act, 1995 (section 2.3). The final section of the chapter forms the main theme of this chapter by concentrating

on the roles and experiences of carers (section 2.4). Hence, formal and informal care and the costs of caring will be discussed accordingly. This first main section of the chapter begins by briefly exploring some of the history, philosophy and political impetus behind the ethos of community care.

## **2.2 History, Philosophy and Political Origins of Community Care**

Community care for older people in Britain has grown sporadically in response to demographic, social and economic changes. These influential factors have not only resulted in different assumptions of how best to care for older people, but also how the role of informal carers needs to be viewed in the provision of social care. There are three main elements that can be discerned from the historical evolution of community care and, hence, the increasing importance of informal care through to the present. These are 1) institutionalisation; 2) the provision of professional and voluntary services in the community to support older people and thereby their carers; and 3) community care as provided by the community. How this shift in focus from formal care to mainly informal care provision for older people evolved is now outlined.

Historically, long-term care provision for older people by the NHS and local authorities was often situated in large impersonal institutions (Audit Commission, 1986). Accordingly, those older people who were seen to need care received formal care, whereas many older people being cared for in the community were not deemed as needing care. The result of this system of providing care was that the focus of care was more on formal institutional services, and the provision of statutory services in the community to aid older people and their carers was basically neglected. In addition, the important contribution made by informal carers providing the bulk of care to older people went unrecognised.

The provision of some professional and voluntary services in the community underpinned the second element in the development of community care, i.e., the provision of social care in the community. Here, the trend was to seek alternative ways of caring for older people and to promote the growth of community care, rather than in institutional settings (Tester, 1996). The principle that it was in the best interests of older people to remain in their own homes for as long as was reasonably possible influenced this new impetus. Thus, services became increasingly available to enable and thereby sustain older people in their homes. To a certain extent this had the effect of also supporting their carers, albeit not in an explicit way. For instance, the 1962 Hospital Plan for England and Wales (Cmnd. 1604) was designed to prevent expensive admissions for institutional care by increasing community health services.

In spite of these objectives, as the 1960s and 1970s progressed, successive reports and policy statements gradually acknowledged the fact that, in reality, the input of professional services, complemented only by fragmented voluntary services, had been inadequate in meeting the needs of older people in the community (Townsend and Wedderburn, 1965; Seebohm Report, Cmnd. 3703, 1968; DHSS, 1977). These reports further asserted that the objectives of 'community care' had not been fully met and the policy was thus seen to be largely ineffective. The question remained as to why these initiatives had been unsuccessful. Firstly, writers have argued that there was no consistent effort to strategically plan or provide effective financial support for community care services, largely because of a rather simplistic perception of care needs of older people. Secondly, the care provided by the families of older people was taken for granted in policy debates (e.g. Walker, 1985; Bulmer, 1987; Parker, R., 1990), and in particular the contribution made by the female carers of these families had been overlooked (EOC, 1982a; Finch and Groves, 1983).

This realisation of neglect revealed that informal carers (mainly the family)-who had been responsible for providing the majority of care needs to older people and had thus absorbed many social, emotional and financial difficulties in the community-were an invaluable and essential resource (Parker, R., 1990). A White Paper (A Happier Old Age, DHSS, 1978) pronounced that families could not be expected to shoulder the entire caring responsibilities for the growing number of frail and older people, and further exhorted that the wider community should give more support. Hence, the beginning of the 1980s heralded the appearance of the third element in the development of community care, namely that of care by the community where informal carers are viewed as an integral part in the provision of social care. The 1981 White Paper 'Growing Older'. (Cmnd. 8173) spelt this out by exhorting that:

*.....the primary sources of support and care for elderly people are informal and voluntary. These spring from the personal ties of kinship, friendship and neighbourhood.... It is the role of public authorities to sustain and, where necessary, develop-but never to displace-such support and care. Care in the community must increasingly mean care by the community'.*

(Para. 1.9)

Clearly, the above policy documents show not only the first steps towards the formal recognition of the contribution made by carers, but also that informal care was to be encouraged. Nonetheless, this need for a reassessment in community care provision for older people towards one which included the wider community also came about because of 1) the predicted increase in the number of older people, many of whom would make heavy demands upon health and social services, a factor considered extremely important in influencing policy (OPCS, 1983); and 2) a realisation that the public purse could not sustain

the full costs of care. The development of private and independent sectors needed to be encouraged. Hence, the 1981 White Paper also asserted:

*'Providing adequate support and care for elderly people in all their varying personal circumstances is a matter which concerns-and should involve- the whole community.....Public authorities simply will not command the resources to deal with it alone'.*

(Para. 1.11)

The above excerpts show that community care policy not only accorded with ideas about traditional responsibilities, but was also seen as a means of achieving greater cost-effectiveness. Nevertheless, in practice the policy was having problems in three main areas (Parker, R., 1990).

Firstly, in the early 1980s, financial incentives encouraged the dramatic increase in expensive admissions of older people to residential homes (Qureshi and Walker, 1989; Parker, R., 1990). Consequently, many older people received institutional care who could have remained in their own homes had better support been available to them and their carers (e.g. Audit Commission, 1986).

Secondly, although Joint Consultative Committees (JCCs) were set up in 1974 and joint finance resources were allocated, it was difficult to secure collaboration between the health authorities and local social service departments responsible for jointly providing care to older people. Thus, a fragmented service provision continued. Receipt of service sometimes overlapped, and was based on what was available rather than on the basic social needs of users such as mobility, personal care etc. In addition some carers of older people were

lacking sufficient outside support and were suffering from the strain of caring. Accordingly, it was argued that the result was poor value for money (Audit Commission, 1986).

Thirdly, the policy was being challenged on its assumptions about the ready availability of informal carers. The strain, under which many of them lived, was brought to public notice. Hence, as a result of studies and reports (EOC, 1980, 1982a, 1982b; Nissel and Bonnerjea, 1982) and the development of the Association of Carers (since 1988- Carers National Association), the caring experience and the contributions from carers became more widely recognised. In particular it became evident that care was in reality family care, and often fell on the shoulders of one member of the family. In addition, the deficiencies of existing community care policies that prioritised older people living on their own rather than those living with their family meant that the needs of carers were neglected (Parker, R., 1990). Policy makers began to realise that, in order to advance community care, policies would formally have to appreciate the unacknowledged care routinely provided by informal carers. Importantly, informal carers thereby became of considerable importance in ensuing policy objectives. With increasing frequency, terms such as 'shared care', 'care for the carers' and 'carer support' were employed in community care discourse (Parker, R., 1990). Thus, the Griffiths Report 'Agenda for Action' (1988), which was a response to the 1986 Audit Commission report, talked about giving support and relief to informal carers (Para. 3.6). Nonetheless, it also advocated that as 'families, friends, neighbours and other local people provide the majority of care' (Griffiths Report, 1988, Para. 3.2) they would continue to be a primary source of community support. The report also exhorted that care and support could be provided from a variety of sources (Para. 3.4). In other words, the imperative behind this focus is that care for older people in the community must increasingly mean care by the community. How this emphasis affects the recognition of carers is now examined.

### 2.3 Care in the Community or by the Community?

Community care for older people has moved from a premise of a large statutory input to a mixed pattern of provision necessitating a wider range of input by private, voluntary and, in particular, informal sources. The Audit Commission Report, 1986 talked about changing the balance of services by providing options of care suited to individual needs. Importantly, the report pointed out that community care would have the effect of substantially reducing the strain 'on the millions of people who are caring for relatives with limited support from public services' (Para. 150). Caring for the carers was therefore also considered a main objective. Hence, the experience of carers and the strain they may endure, have clearly been recognised by policy makers. As a response to the Audit Commission Report, 1986, the proposals made in the Griffiths Report 'Agenda for Action' (1988) set out formally to address the contribution made by informal carers and to try to ensure that they were not exploited by strengthening support for carers.

It has been argued that care in the community has two objectives: firstly, in providing '...an opportunity for low-cost solutions to social problems through utilising informal caring networks' (Levick, 1992: 79); and secondly, as '...a remedy for the financial problems facing the health and social services' (Graham, 1992: 444). Not only was the state unprepared to sustain the expense of institutional care, it was also unable to pay for the increasingly wide-ranging health and social services required to enable older people to be supported in the community (Parker, G., 1990). Thus, it has been argued that a period of public expenditure retrenchment with the focus on informal carers and older people as a priority group has resulted in attempts to deliver services at a lower cost. Rather than providing effective services to support the majority of informal carers, they are, in effect, seen as a substitution for formally organised services (Bamford, 1990). An anomaly can be

said to exist in the concept of substitutability. On the one hand, a mixed provision of care is related to the belief that it is not only preferred by older people and their families, it is also more efficient and of a higher quality to users and carers. On the other hand, because of the rapid increase in need, more of a premium has been placed on informal carers. The arguments regarding the substitution of care do have some basis in that it is estimated that informal carers are saving the Government £34 billion per annum (as reported by Mihill, 1995 and The Princess Royal Trust, September, 1998 based on information from the Institute of Actuaries). Nonetheless, it is clear that the community care legislation is underpinned not only by values to improve choice and preferences of resources according to the needs of older people and their carers as consumers of services, but also by the recognition of carers.

### **2.3.1 Care Acts of 1990 and 1995**

This section of the chapter outlines some of the main changes that have taken place and which have resulted in the NHS and Community Care Act, 1990, fully implemented in April 1993 and the Carers (Recognition and Services) Act, 1995, which came into force on 1st April, 1996.

Several reports have contributed to the NHS and Community Care Act, 1990. The highly influential 1986 Report from the Audit Commission called for a radical change in the provision of care. The criticisms arising from this report prompted the Griffiths inquiry (Griffiths, 1988) to look at the organisation and funding of care which focused on the ideals of community care. The White Paper entitled *Caring for People: Community Care in the Next Decade and Beyond* (Cmnd. 849, 1989) was the response to these reports, and its objectives were enacted in the NHS and Community Care Act, 1990. It not only set out the

framework for the present innovative community care reorganisation, but also focused on the important role of carers within policy.

Key changes include the role for local authorities to act as agencies for development in order to stimulate a supply of services from voluntary and especially private sources, without necessarily acting as providers. In addition, local authorities are also meant to act as allocators of resources by determining the criteria of eligibility for services. Main responsibilities are to produce and publish clear plans for the development of community care services; to establish complaint procedures; to monitor the quality and cost-effectiveness of services and to assess eligibility for financial assistance. Clearly, these key changes have implications for the organisation, structure and form of service delivery and for the type and quality of care provided to individuals and their carers.

Six key objectives for service delivery were articulated in the policy guidance *Caring for People: Community Care in the Next Decade and Beyond* (Cmnd. 849, 1989):

- *to promote the development of domiciliary, day and respite services to enable people to live in their own homes wherever feasible and sensible;*
- *to ensure that service providers make practical support for carers a high priority;*
- *to make proper assessment of need and good case management the cornerstone of high quality care;*
- *to promote the development of a flourishing independent sector alongside good quality public services;*

- *to clarify the responsibilities of agencies and so make it easier to hold them to account for their performance:*
- *to secure better value for taxpayers' money by introducing a new funding structure for social care.*

Cmnd, 849, (Para. 1.11)

Of all the above objectives, it is the second point on ensuring that service providers make practical support for carers a high priority that is the most directly relevant to this thesis. The fact that support to carers is seen as a priority can be considered a major step forward in acknowledging the social, emotional and financial costs carers may incur as a result of their caring role. As argued by Parker (1992), services received are an important aspect in helping carers to cope, and given that the success of community care initiatives depends on carers continuing to provide care, this objective is one of the most important.

One further aspect is that community care changes are underpinned by the premise of consumer choice. For carers of older people (as consumers), one fundamental choice is surely whether they wish to become a carer, and, if so, what kind and how much support they can expect that helps maintain their own health, morale and financial security (Potter, 1993). When current policy objectives actually place the onus on more people to care, it is difficult to see how individuals can make a completely free choice to adopt the caring role. Therefore, it should be made absolutely clear as to how much choice carers actually have in electing to care (Robinson and Yee, 1991). For those that do decide to care, it has to be recognised that they are very much individuals who have specific preferences and needs. However, it is also important to understand that many carers do not see themselves as

carers, but simply as husbands, wives, daughters and sons; it may thus take many years for someone to realise that they are a carer (Sutcliffe, 1989). Many carers consequently remain unidentified by the formal sector and would not benefit from available provisions and allowances, which may help to reduce strain and help them to cope. Accordingly, practical support to carers as a priority needs to be made visible and proactive if community care policies are to succeed in aiding carers.

One objective also relevant to making practical support to carers a priority is to make proper assessment of need and good case management the cornerstone of high quality care. Section 3.2.6 of 'Caring for People': Community Care in the Next Decade and Beyond (Cmnd. 849, 1989) states that: '(a)ssessments should take account of the wishes of the individual and his or her carer, and of the carer's ability to continue to provide care....'; and that: '(e)ffort should be made to offer flexible services which enable individuals and carers to make choices.' There are two important factors contained within these two statements, which need to be discussed.

Firstly, the statements imply that assessments should consider the carer's ability to continue to provide care. It has been argued that it is possible that older people with the same degree of dependency may be given different priority on the basis of the carer's ability to cope (Lewis *et al.*, 1997). Consequently, where a carer is judged to be coping, they may receive a lower priority score. Nonetheless, the Carers (Recognition and Services Act), 1995 has strengthened the individual position of some carers in that it gives carers who regularly provide a substantial amount of care legal access to assessments in their own right when requested. However, not only is the onus on the carer to ask the local authority for such an assessment, it also depends on how the local authority determines what is classed as

substantial. Thus, depending on the area, some carers will receive the help they need and others will not.

Secondly, in relationship to flexibility of services and choice, it is argued that if assessment is separated from provision then the needs of older people and their carer can be objectively assessed. A care package can then be constructed from a range of services. Realistically though, need, resources and services available will determine choice. Therefore the effects of community care changes may actually limit choice to individuals and result in available services being inappropriate. The needs of older people and their carers are in effect judged by the local authority and its agencies who decide, on the basis of a needs assessment, who will receive care, what type, how much and so on. A needs-led approach to assessment and service provision may indeed differ from the expectations associated with choice as the difference really lies with need and demand. Hence, some carers may feel that they are not receiving the appropriate level of support to meet their particular needs.

One final objective which also relates to making practical support to carers a priority, albeit indirectly, concerns the responsibilities of agencies whereby they are held accountable for their performance. Collaboration between health authorities and social service departments is the first important principle emphasised in guidelines. Joint planning and joint management are seen as imperative for the realisation of policy objectives aiming for integrated seamless care to users (Hallet, 1982). Unfortunately, past history has shown that collaboration may be difficult to achieve (Parker, R., 1990). One first requirement is clarity about agreed responsibilities of roles between the core public bodies like health and social services. The distinction between health and social care is not clearly defined and neither is it exempt from economic pressures which influence authorities to limit their responsibilities

(Wistow, 1994). Indeed it is argued that the needs of those in receipt of community provision rarely precisely fit into the bounds of either the health or social services (Evers *et al.*, 1991). Hence, older people and their carers may be affected by a health and social care divide in which some services are diminishing. For instance, bathing services constitute a grey area, being neither a health nor a social imperative (Robinson, 1991). In addition, there is the issue regarding the invaluable provision of respite care, which is viewed more as a social admission. Therefore, health authorities question whether they should be responsible for its provision and funding. Further disputes arise in other areas of care provision, for example older people and carers in need of essential aids are being shunted between their health authority and their local social services department with neither wishing to accept responsibility for the provision of equipment (Potter, 1993). At the same time, older people and their carers may be informed that, because of insufficient funds, they must wait until the beginning of the new financial year to obtain equipment. Naturally, carers are aware that some services are not readily available from health and social services. Nonetheless, many carers will need and, arguably, have a right to assistance with practical and personal care tasks. Carers need accurate information about who is accountable for what and how either agency prioritises their services so that they have a realistic idea of what they can, or cannot, expect.

The NHS and Community Care Act, 1990, and the Carers (Recognition and Services) Act, 1995, formally recognise the importance of informal carers, and are undoubtedly designed to enhance the experience of caring. Nevertheless, the discussion above has shown some of the pitfalls regarding the implementation of community care objectives. One hopes that community care policy will in practice live up to expectations and that service providers are able to meet the needs and preferences of users and carers.

## 2.4 The Role of Carers

Research has shown that most daily care for older people in the community is provided informally (Griffiths, 1988; Green, 1988; Qureshi and Walker, 1989; Sinclair, 1990; Smale *et al.*, 1994; Berthoud and Beishon, 1997), supplemented by the services from health, social care and voluntary agencies. Individuals care for others for a variety of different reasons and values. Indeed, caring takes place in a relationship and it is the nature and history of that relationship which gives rise to caring for someone and assuming the role of a carer. It is this reality which influences not only how carers view their situation and daily lives, but also how carers are perceived by society, statutory bodies, service planners and providers.

Although community care objectives are designed to meet the needs of both the older person and their carer, within the concept of caring there lies an inherent difference of interests between the providers of care and those in receipt of it. Therefore it is fruitful to explore the basis of caring, its sources and nature of relationship, and how it is conceived and experienced by formal and informal providers of care. Weiss (1969) concluded that all relationships are based on particular assumptions, which address emotional and cognitive aspects rather than social roles employed. Weiss's typology distinguished between relationships which provided for 'social integration', 'reassurance of worth', 'intimacy', 'assistance' and 'guidance'. These points will now be outlined and explored more fully both in relation to carers' experience, and in their relevance to the policy dilemmas for community care concerning the linking of formal and informal systems in the care of individuals in the community, namely a continuum of care.

'Social integration' occurs in relationships where members share the same concerns and situations. Information, experiences and ideas can be exchanged. Carers may often feel

isolated in their role, particularly when they are heavily involved in caring. For example, carer self-help/support groups can offer social as well as emotional support (Twigg *et al.*, 1990; Tinker *et al.*, 1994). Contact with such groups may therefore provide carers with the necessary assistance, which may enable them to continue in their caring role.

'Reassurance of worth' involves a relationship in which an individual is valued and respected for his/her competence in a given role. In carers this can be exhibited by an expression of appreciation by the person they are caring for (Grant and Nolan, 1993) or indeed by significant others such as health and social care professionals who need to look to the wider situations of carers than purely practical issues (Lewis and Meredith, 1988). Appreciation expressed or perceived may thus constitute recognition of their contribution.

'Intimacy' is provided in relationships from which individuals can draw a feeling of confidence and worth. Here, people can be themselves and express themselves freely without fear. Attachment is provided by marriage or partnership and by close friendship or relationship with others. This factor may often form the basis for caring. Indeed caring takes place in a relationship, usually kinship, or because they have formed primary social bonds with the person requiring care (Twigg and Atkin, 1994).

'Assistance' depends upon a relationship, which trusts in the supply of services and resources of family, friends and neighbours. Carers do look to their informal network for support in their caring role (Lewis and Meredith, 1988). Previous work on carers has found that satisfaction with help from relatives was significantly correlated with carer morale (Gilhooly, 1984). Consequently, help from an informal network may also be of importance in enabling carers to continue to cope with their caring role.

'Guidance' concerns a relationship which is based on the interaction (not necessarily face-to-face) with respected others. for example, a priest or health and social care professionals. This component incorporates the importance of statutory input such as counselling (e.g. Richardson *et al.*, 1989) in the caring process and is therefore crucial in how carers not only cope with their role, but also maintain a sense of well-being in supporting older people in the community.

Weiss's (1969) typology of relationships helps to explain the bases of caring as well as sources of formal and informal social support for carers. Naturally, being able to draw on both formal and informal areas can only aid carers in their role. An interweaving of care between formal and informal systems with a seamless service for carers is highly desirable for those responsible for the planning and delivery of care. On the one hand, it utilises resources in the community, and on the other, it is considered cost effective for society as a whole. However, how does this impact on carers' roles, and how do carers fit into the scheme?

Carers occupy an ambiguous position within the social care system, as they are not often the main focus for intervention (Twigg and Atkin, 1994). Carers are traditionally neither client nor patient. Nonetheless, an increasing awareness of their interests means that they feature prominently in policy initiatives and are included in wider debates on welfare concerns: hence, the recent implementation of the Carers (Recognition and Services) Act, 1995. In spite of positive statements in support of carers, ambiguities have been conceptualised in terms of different models of how carers' roles may be perceived and categorised by formal agencies at any one time. How carers are viewed affects the experience of caring for an older person.

Twigg and Atkin's (1994) classification of four models relating to carers is particularly relevant to this research, in that they clearly show the significance of carers in the service system. In their first model, carers may be seen as a basic resource. This is largely because care has been, and still is, predominantly provided by the family (Parker, G. 1990). Furthermore, care is based on aspects such as personal ties and in many instances reciprocity (e.g., Motenko, 1989; Qureshi and Walker, 1989; Finch and Mason, 1993). Within this reality, informal care provision is thus seen as taken for granted by social care agencies, and statutory care input is only required where an informal support network is not readily available. Indeed, as reported by a social services planner to Walker and Ahmad (1994: 642) in their survey of care providers, 'something is not considered a need unless it is not being met by relatives'. Importantly, Walker and Ahmads' impression was not that service professionals themselves are offhand in their attitude. rather this was at the heart of how the policy works in practice. It appears that the general perception of carers is on the one hand that they are doing what is 'normal'. On the other hand, carers are providing a vital role for society, which may involve various physical, social and emotional costs. Despite carers' contribution, Twigg and Atkin (1994) argue that any tensions between the needs of carers and the cared for is virtually ignored in the service system, and any concern with the well-being of individual carers and how they cope with their role is marginal within this system.

Twigg and Atkin's second model regards carers as partners in care. Here carers are seen as co-workers in a continuum of care. Therefore, the caring process is viewed as one of shared responsibility based on mutual support. This model has great appeal to service planners and providers. Nonetheless, in practice conceptual difficulties and logical obstacles exist, for example the recognition of power differentials in different caring relationships and the

ability to strike a balance between the needs of the older person and those of the carer (Robinson and Yee, 1991; Smale *et al.*, 1994).

Some of the assumptions underlying a continuum of care need to be more fully explored if the policy objectives concerning the roles of carers are to be understood and realised (Bulmer, 1987). Simply put, the notion of carers as co-workers tends to be superficial and ignores that conflict of interests between the two systems are inherent. One example is in the allocation of resources and the extent of service provision available to individual carers. Carers rightly expect service providers to support and help them to receive appropriate and adequate services to meet their needs. Given that local authorities both purchase and ration services, the concern is that packages of care developed at the assessment stage will focus not on what is best for the user and their carer, but on what is cheapest. As indicated in section 2.3.1, there is concern that conflicts of interest may arise between the two authorities responsible for the provision of community care, namely a health and social care divide in who pays for what. According to Janice Robinson (currently the Programme Director of Community Care, King's Fund Carers Unit): '(t)he black and white division is throwing up grey areas which need to be resolved if a seamless service for carers and users is to be achieved' (1991: 4). In addition to conflicts between health and social authorities, discord may equally exist between informal groups such as along age, gender, and social lines or between different ethnic groups. Here, people's relations with their neighbourhood may often be characterised by a degree of social distancing (Abrams *et al.*, 1989). One example of this might be a local carer group attended mostly by women where male carers feel out of place.

The above discussion concerning obstacles to a continuum of care has merely outlined some of the difficulties associated with the collaboration of interested parties in the provision of care. This is not to say that it is not possible or desirable, but that more thought and planning is needed if carers are to be properly supported and their experience and roles within the system are to be understood.

In Twigg and Atkin's (1994) third model, heavily involved carers are seen as co-clients and as equally and legitimately deserving of available services to help them in their role. The objective is to ameliorate stress and improve morale. Services such as respite care are regarded as distinctively beneficial to carers. It is with this model that the recent Carers (Recognition and Services) Act, 1995 may prove to be of major importance to carers.

Finally, according to Twigg and Atkin's (1994) fourth model, there may exist a relationship where carers no longer have the responsibility to care. Carers are superseded either because the cared for person becomes independent or because carers are persuaded to give up their role in order to improve their own health and well-being (e.g., Levin *et al.*, 1989).

The points raised above are important in that they demonstrate the unsystematic way in which formal care provision may operate and how it may impact upon informal carers of older people. Carers' contributions may be formally recognised and government policy is designed to support carers. Nonetheless, carers are not always considered the main client and any support they do receive therefore tends to be secondary to the needs of the cared-for person. Carers often continue in their role precisely because of the relationship which goes before them, and many see their role as one of duty and obligation (Pitkeathley, 1992). Although duty and obligation are not necessarily entirely negative reasons to care, and may

subsume motives such as love, it does mean that some may carry on caring against their own interests. It is for this reason that policy makers have a duty to ensure an equitable, accessible and appropriate service to individual carers so that the objectives enacted in the NHS and Community Care Act, 1990, can only better the experience of carers.

Against the background of how carers may be viewed within the caring continuum, it now becomes pertinent to explore the organisations involved in the process of change within community care reforms. This next section of the chapter is therefore concerned with the first and fourth objectives of the White Paper (Cmnd.849, 1989) outlined in section 2.3.1 and the modes of formal care provision and its funding to older people and their carers.

#### **2.4.1 Formal Care Provision, Usage and Impact**

Formal care can be provided from both the independent and the statutory sectors. Studies have shown that it is statutory mainstream services which have provided the majority of formal help to individuals and their carers in the community (Levin *et al.*, 1989; Twigg and Atkin, 1994). However, as community care changes have emphasised the need for a plurality of services in a mixed economy of welfare, this situation is rapidly undergoing change. The statutory sector is no longer the monopoly provider of community based services, and the independent sector can and does provide all the services for older people and their carers. Nonetheless, the extent, use and costs of private help to this group in the community are less clear. Although at present provisions from this area are flourishing, given the limited literature available on the current wider use of the independent sector, its usage and impact of services on older people and their carers will be briefly considered. Service provision from the statutory sector will then be discussed in more detail.

The bulk of private care provision for older people has hitherto been found in the provision of places for older people in residential and private nursing homes which grew at a rapid rate during the 1980s (Parker, R., 1990). This was largely financed through the social security system at the expense of the public purse (Hughes, 1995). Organised care by private companies has, since community care policy imperatives, become well established. One important factor not highlighted in current legislation is that, ideologically, private care is based on demand and not need. This therefore poses questions for the future, given that such services need to be more available to users such as carers of older people. As pointed out by Parker, R. (1990), much depends on people's level of disposable income and whether they are willing to spend that money on private domestic care services, especially if a substantial amount of help is required over a long period of time. Naturally, if such provisions were more available from local authorities to aid carers in their own right, there would be less need for services from private care organisations which may often be at a greater cost to users. On the other hand, carers may feel more in control if they are directly employing helpers from the private care service sector.

Historically, voluntary agencies have been formed as a response to inadequacies in care provision (Leat, 1990). Therefore the voluntary sector encompasses a wide variety of schemes and activities such as national and local campaigning and fund-raising, local domiciliary visiting schemes, neighbourhood care schemes, the provision of aids and equipment and the provision of day care places and respite care. The voluntary sector also includes major national voluntary organisations such as Age Concern, which primarily focus on older people themselves. Organisations developed particularly for carers include the Carers National Association, as well as more small-scale local self-help and neighbourhood groups and advisory centres. Voluntary organisations therefore often

represent different interests such as those organised along ethnic lines, for example community groups for Asian women and girls (Dostiyo in Northampton), and groups for older people of Asian origin (Shanti group in Kettering). They may also become very specialised in their field and consist of highly trained or experienced paid or voluntary workers, for instance the Alzheimer's Disease Society who can offer invaluable information and support to carers of older people with this chronic condition.

Some problems as to usage and impact have been outlined, in that voluntary organisations with high funding are able to attract more volunteers and that availability of volunteers is unevenly spread between groups and projects (Hatch, 1980; Leat *et al.*, 1986). In addition, other work has found that more affluent areas tend to have a more highly active voluntary sector (Wilson, 1994). This consequently leads to difficulties in ensuring a wide coverage and equity of service. Furthermore, often overlooked is the fact that voluntary services have organisational expenses and therefore financial constraints, which again limits their individual effectiveness. At the same time, they may also provide good value for money services which, if provided by the local authority, would be at a greater cost (Hatch, 1980). As the voluntary sector is so varied and there is currently no national data on the scale of voluntary provision available (Leat, 1990), it is difficult to evaluate its effectiveness for older people and their carers. Having said that, many minority ethnic voluntary groups in particular play a major part in the lives of their community (see Chapter 3, section 3.6.1). Funding from local and central government to the voluntary sector has to be offset against unquantifiable benefits, such as the numbers of older people and their carers helped and advised, thereby reducing demand on the state's limited resources. Community care changes, which involve the contracting of some voluntary services, may alter funding levels to the voluntary sector as a whole. This means that some voluntary groups, which relied on

local authority grants will be unable to survive, with the result that some particular services older people and their carers previously relied upon may no longer be accessible. At the same time it is important to note that, as services provided by local authority agents become more restricted, more pressure may be put on voluntary organisations and groups to make up for this shortfall (Walker and Ahmad. 1994).

It has been indicated, that the bulk of help to older people from formal sources has traditionally been provided by the statutory sector (Levin *et al.*. 1989; Twigg and Atkin, 1994). The various public bodies, such as health and social services, have been created by law to provide essential support to those in need and are funded by the public purse. Statutory provision for community care comes largely from both local authorities and the National Health Service (NHS). Most health services are free at the point of receipt such as through hospital care, General Practitioners (GPs), community nurses etc.. whereas many local authorities now charge for statutory services provided in the home. Examples of this are home-helps, meals-on-wheels etc.. as well as a charge being made for some services outside the home, for instance day care and respite care. Facilities and costs for such services do vary across the nation and therefore the usage of these services by older people and their carers may also vary according to what people can afford. As pointed out by Robinson and Yee (1991), whether or not carers pay for services may depend on who is providing them. For instance, respite care provided by the health service is free, whereas when local authorities provide it there may be a charge. In addition, many older people and their carers may be on a low income, yet they may have to pay for services that previously were available at little or no cost to them. Clearly, service provision to support carers should not depend on their ability to pay.

While statutory services are often primarily aimed at the older person themselves, the impact of mainstream services, on carers in particular, can be enormous. As documented by Parker (1992), help from others in their informal network, provision of services and time off caring were main factors in helping carers to cope. It is these latter two elements in their relationship to carers that are important in this study for the discussion on statutory service provision. Therefore, in this section of the chapter, the discussion will focus on some of these main services used by older people and their carers. Home-based care, day care and respite care will be discussed accordingly.

The home-help service has been the most widely used domiciliary service by assisting more people than any other personal social service (Sinclair and Williams, 1990). Figures from 1994 (CSO, 1996), state that a total of 9% of households in England, where the oldest member was aged 65 years or over, either purchased or were provided with this service by their local authority. The home-help service is also the most valued of services received by older people and carers (Arkley, 1964; Levin *et al.*, 1989). In addition, it has been found to be significantly correlated with carer morale (Gilhooly, 1984). Its provision is, however, largely focused on older people living on their own or older couples where both partners are seen as clients (Twigg, 1992). In the case of a male carer supporting an older person suffering from dementia it has been shown to delay the need for residential care (Levin *et al.*, 1989). The service is often commended by carers for the practical help it provides. It further helps carers of older people by allowing them to get out for a short while and have a break. In addition home helps provide company and emotional support (Twigg, 1992).

Home-help duties include domestic tasks such as cleaning, physical tasks such as washing and dressing clients, and social duties such as assisting with shopping. During the 1980s the

home-help service was redesignated as home-care service (Hedley and Norman, 1982; Tinker *et al.*, 1994). The change in its name reflects the shift during the 1990s to one that emphasises personal care. Unfortunately this included a much diminished cleaning service which some carers needed; carers felt forced to give up the receipt of home-care as a result (Twigg and Atkin, 1994). Naturally, such a service remains extremely important to older people if they are encouraged to stay in their own homes. The move to a more personal care service is also reflected in a survey quoted by Fry (1992), which found that 17% of home-helps were performing medical tasks, for example administering drugs or giving injections. As can be seen, a satisfactory home-based care system may therefore contribute immensely to the normal everyday lives of many older people and thereby their carers. It is not surprising that they have been described by carers as the most important relationship they enjoy with any service provider (Fry, 1988). However at present, due to community care changes, there is some debate about how this service should be used. Should it continue to provide basic tasks to many or should it provide more intensive and frequent services to fewer but more dependent older people? Clearly, such questions will have an impact on those carers who value these services and who expect to be in receipt of these services in the future.

Day care is also a form of mainstream service, which may be provided to an older person with a direct intention of relieving the carer, especially when the older person suffers from a dementia. According to the GHS (1985) data, approximately 27% of people aged 65-84 years and over who had a carer had attended a social club/day centre in the month prior to the interview. Again, there is sufficient evidence to suggest that carers appreciate day care provision both for the relief it may bring (Twigg and Atkin, 1994), and for the opportunities it gives them to get out and pursue their own interests (Levin *et al.*, 1989). In addition,

carers of older people with dementia found it of immense value to their well-being in a sense that their load was being shared (Levin *et al.*, 1989). The growth of statutory day care facilities in the 1960s and 1970s provided an alternative to hospital or residential care (Sinclair and Williams, 1990). It was also considered that the service significantly delayed or prevented permanent institutionalisation (Fennell *et al.*, 1981; Twigg and Atkin, 1994), but in practice, statistical evidence for this is lacking (Twigg, 1992; Sinclair and Williams, 1990). For older people themselves, day care attendance may provide opportunities for reminiscence, which importantly allows older people to talk about their experiences in life and provides for social interactions with others in the group (e.g. Buchanan and Middleton, 1994; Coleman, 1994; Buchanan and Middleton, 1995). Clearly, if the older person also perceives some positive value from attending some form of day care, then the more likely they are to be happy to want to go, thus relieving the carer of any guilt they might feel in needing some time to themselves.

As with other statutory services, there are differences in the amounts and specialisations of day care facilities obtainable throughout the country. Problems with satisfactory day care systems include the availability and cost of transport, the unreliability concerning times older people are collected and delivered, and inflexible weekday opening hours (Fennell *et al.*, 1981). There is also some evidence that older people who are deemed too difficult to care for are refused day care because staff are unable to cope with their particular needs (Lewis and Meredith, 1988). This forces the carer to assume sole care if, for example, specialist psychogeriatric day care is limited in their area. Day care facilities on their own cannot always cater for all the needs of someone who is severely disabled (Sinclair and Williams, 1990). For carers who find it difficult to cope there is a need for day care to be integrated with other forms of services, which offer the carer more of a rest.

Respite services such as those found in local authority homes, private residential homes and designated respite units offer the carer a more complete break by assuming responsibility to care for a given period. In addition, some geriatric hospitals offer this service on a regular basis to carers heavily involved in caring for an older person on a full-time basis. (e.g., St. Mary's Hospital in Kettering, Northamptonshire). Recent information has shown that hospital trusts are cutting bed provision in respite facilities thus denying many carers a break from caregiving responsibilities (Glen, 1997). This is a pity as it is a service directly aimed at providing respite for carers (Allen, 1983), although some health care professionals find it difficult to justify respite care purely to give carers a break (Tyler, 1987). This ethos may therefore have an impact on the numbers of carers gaining access to respite care facilities (Twigg, 1992). However, the recent publicity concerning carers and their need for the provision of respite care (Hibbs, 1999) may serve to change this outlook.

The 1985 General Household Survey (Green, 1988) reported that 65% of spouse carers and 44% of those caring for a co-resident parent and who cared for at least twenty hours per week would find it either very difficult or impossible to arrange alternative care for two days. In addition, it reported that 57% of co-resident carers and 35% living in another household had not had a break of at least two days since they had started caring. The exact numbers of carers of older people, including spouse carers, who received respite care are unclear, however as studies have shown, very few older people being cared for by a spouse had either received or indeed wanted respite care (Allen, 1983; Levin *et al.*, 1989). Many carers of older people, especially the family, feel ambivalent about accepting institutional based respite (Twigg, 1992), although they might welcome the break. Different factors may account for this. For example, Parker (1993a), looking at spouse carers, and Lewis and Meredith (1988) in a study of mothers and daughters, reported that tensions and dynamics

within the relationship play a significant part in determining whose interests predominate. It has been reported that many carers would only use formal respite services if their physical or emotional health were in danger (Gonyea *et al.*, 1988). Nevertheless, respite care is mostly used by carers of older people, particularly those suffering from a dementia (Twigg, 1992). Evidence concerning respite facilities for carers has shown that it is beneficial (Bose, 1990). Carers regard it as important in their ability to cope (Allen, 1983; Levin *et al.*, 1989; Twigg and Atkin, 1994), and in conjunction with day care it may reduce carers' stress levels (Levin *et al.*, 1989). Conversely, studies have shown that respite care is positively associated with admission (Levin *et al.*, 1989), and others have reported it is sometimes regarded as a preparation for long-term residential care (Allen 1983; Solomon, 1992). As such, it may not act as an effective method of preventing institutionalisation. Carers' quality of life can be improved. Those who do feel they need respite service tend to re-use it and express high satisfaction with it (Solomon, 1992). It is hoped that the £140 million promised by the Government for respite care (Hibbs, 1999) will filter through to even more carers of older people who want and need a break.

The services outlined above provided by the statutory sector often serve an important social function for carers, in particular for those heavily involved in caring. However, carers often have a variety of needs for which no single service alone is sufficient; effectiveness of one service may depend upon the receipt of another. Proper and considerate packages of care are essential in meeting the needs of many older people and their carers.

#### **2.4.2 Informal Care**

This section of the chapter will concentrate on the nature of care and the numbers and characteristics of carers nationally, with specific reference to carers of older people.

Informal care has become a principal issue for those involved in current social policy. Until the mid 1980s any estimate of the numbers and characteristics of people caring for older persons or other dependants was a matter of informed guesswork (Parker, G., 1990). At the request of the DHSS, a series of questions regarding informal care was included in the General Household Survey (GHS: 1985, 1990). The main aim was to provide national estimates of the number of informal carers from a nationally representative sample. For the first time, this information clearly indicated the extent of informal care in the community. Carers were defined as those looking after or regularly providing a service for dependants, such as the sick, handicapped or elderly who either co-resided or lived elsewhere. Carers were identified by two 'screen' questions<sup>1</sup> and interviewed accordingly. The 1990 GHS survey (a monitor updating the main findings of the 1985 GHS) indicated that more than 6.8 million (1 in 7 adults), in Britain are carers. Recent figures show that there are an estimated 68,000 carers (Glen, 1997) in Northamptonshire, which constitutes 1% of the national total.

The age structure within the population of older people has changed. OPCS figures from 1995 show that the population aged 75 and over has risen from 4% to 7% over the past thirty years. This increase is expected to reach 11% in England and Wales by 2031. The experience of an ageing society is therefore totally new, and one that has now been recognised as a major issue regarding policies concerned with the future need for care. These demographic changes have important implications for individual families. Frequent references have been made to the numbers of very old people and the consequent expected

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<sup>1</sup>Q.1 Some people have extra family responsibilities because they look after someone who is sick, handicapped or elderly. May I check, is there anyone living with you who is sick, handicapped or elderly whom you look after or give special help to (for example, a sick or handicapped or elderly relative/husband/wife/child/friend etc.) (SPECIFY ALL HOUSEHOLD MEMBERS) ?

Q.2 And how about people not living with you, do you provide some regular service or help for any sick, handicapped or elderly relative, friend or neighbour not living with you?

demand on services (Sinclair *et al.*, 1990) and especially to those living alone (Growing Older, Cmnd. 8173, 1981). Further reference has been made to the decreasing number of potential carers (Nissel and Bonnerjea, 1982) and women's participation in the labour market (CSO, 1983, 1986). These concerns regarding the nature of care needed, and the capacity of the community to care for older people is now discussed.

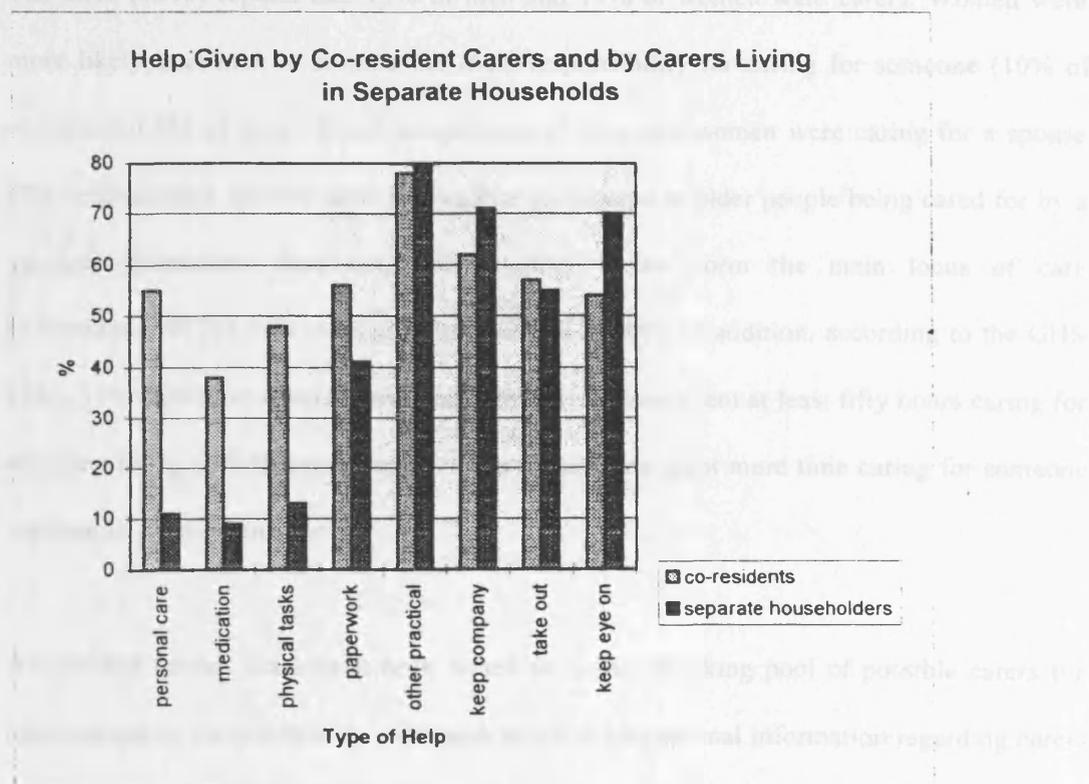
Government statistics show that over one half of people aged 75 years and over reported that in general they were in good or very good health. (OPCS, 1993). Older people may also express more satisfaction with their lives than younger people (Coleman, 1992). Nonetheless, the incidence and severity of disability increase with age, with 50% of people aged 75 years and over reporting a limiting long-standing illness (GHS, 1993). Older people are therefore more likely to use health and social services. Studies have shown that older people are more likely to have some degree of sensory disability (Victor, 1991), to have bouts of acute illness, and/or suffer with a chronic disability which limit their daily living activities (Newman, 1995). Figures from the GHS (1987) show that older people aged 75 and over not only have the highest average number of outpatient attendances (177 per 100 persons per year), but also the highest proportion of inpatient stay (16% in 1987 rising from 13% in 1982). However, not all older people require special care and not all older people with a disability need help on a daily basis. Dependence on others for support varies between individuals and according to how their disability is affected by the environment in which they live (Morris, 1993a; Morris, 1993b). For instance, the availability and provision of aids and equipment and specially adapted accommodation enable many older people to be largely self-caring. Therefore, the impact of their disability and their need for support may to some extent be determined by social and environmental factors. Again, this has important implications for individual families, the community and future policy objectives.

Research has shown that the majority of older people are capable of looking after themselves in their own homes with minimal support (Qureshi and Walker, 1989). In their study of older people and the need for care, Qureshi and Walker found that where help was required for personal care and domestic chores it was given on a regular basis with a high level of frequency and mostly by the informal sector. Similarly, research has shown that the main carers of older people are families themselves, particularly women (Nissel and Bonnerjea, 1982; Qureshi and Walker, 1989; Condy, 1994). Informal care systems depend on personal ties and this means that its provision can be uneven. At the same time, 'informal care-givers remain the first point of reference for people seeking help' (Bulmer, 1987: 177). Carers can respond almost immediately to any health or domestic problem and importantly provide everyday assistance such as supporting older people in their daily lives and helping them to cope with normal life problems. Although most care that older people need can potentially be provided by either informal or formal carers, it is often the individual's informal network, which is known and trusted that allows flexibility and which can provide all kinds of services on a personal basis that provide the bulk of care. It is for this precise reason that informal carers feature strongly in the care needs of older people.

Carers provide all kinds of help and support to older people. The nature and type of care given by the informal sector varies enormously according to their relationship with the carer and the extent and nature of the dependant's disabilities. For example, as well as the family, friends, neighbours and other local people, have been presented as the bedrock of care in the community (Griffiths, 1988: Para. 3.2). Nonetheless, their role as main carers appears to be limited (Green, 1988; Sinclair, 1990), with most providing help with sitting, shopping and other general help. The tasks undertaken by informal carers generally range from providing relatively minor assistance with domestic chores to 24-hour care and support.

The General Household Survey (1990) report on informal carers documents various types of help given by carers who co-reside with people requiring care, and carers living in another household. The caring activities listed are not categorised according to the age of the person being cared for. Nonetheless, the percentage of adults caring for an older person is higher than for any other group (76%). This data therefore gives a clear indication of the varied nature of tasks carried out by informal carers of older people. Figure 2.1 exhibits this information.

**Figure 2.1 GHS Data on Types of Care Given by Residence**



Source: The General Household Survey (1990:7)

The above statistics and other research argue with the popular misconception in modern society that the family no longer cares for older and disabled people (Arber and Ginn, 1990; Parker. G., 1990). Figures show that only 3% of the over 65 population are in institutional care, and there has been no increase since the turn of the century (Victor, 1991) despite the rise in the percentage of older people. This indicates that either fewer older people need care, or more older people are not being cared for, or, as is more likely, they are cared for informally. Research affirms the continuing importance of the extended family (Finch and Mason, 1993) and involvement with friends and neighbours (McGlone, 1994).

The GHS (1990) reports that 13% of men and 17% of women were carers. Women were more likely than men to assume the main responsibility for caring for someone (10% of women and 6% of men). Equal percentages of men and women were caring for a spouse (2% respectively). Studies have shown that, in relation to older people being cared for by a younger generation, daughters and daughters-in-law form the main locus of care (Townsend, 1957; Levin *et al.*, 1989; Parker. G., 1990). In addition, according to the GHS 1985, 51% of women carers compared with 39% of men spent at least fifty hours caring for someone living with them and more women than men spent more time caring for someone residing in another household.

As outlined earlier, fears have been raised as to the shrinking pool of possible carers for older people in the community. Although specific longitudinal information regarding carers is not available, certain changes affecting this group will now be discussed.

Changes in family size may have a considerable impact. The birth rate has declined following peaks in birth in the late 1940s and the mid-1960s (OPCS, 1983) which may

mean that more older people will have few or no immediate kin to care for them. Furthermore, widows and widowers previously receiving care from their spouse will find it difficult or impossible to cope following the death of their partner.

Alterations in marriage patterns such as the increase in divorce and remarriage may make responsibilities for parental care less clear in relation to parents, step-parents and parents-in-law (Parker, G., 1990). At present, no sufficiently large studies have been carried out to determine the extent of obligation to older people which is transferable in reconstituted families.

Women's participation in the labour market (the traditional carers) has also raised concern as to the capacity of the community to care, although available evidence does not support this fear (Parker, G, 1990). According to the GHS (1990), a total of 68% of women carers aged 16-64 years were in paid employment (28% of whom were in full time employment). Therefore, as older people are the largest group requiring care, it does not appear that women are caring any less. In addition, it indicates that the majority of women of working age providing informal care also combine it with paid employment. Moreover, according to Parker G. (1990) the largest increase in women taking on paid employment were married women aged 45-59, and as reported by the GHS (1990) the peak age for caring was in the 45-64 age group of which women formed the largest number (24%). However what the GHS (1990) did not report was how many women in paid employment had to give up work or reduce hours of work in order to devote more time to caring.

Although women, especially single women, are often considered the traditional carers, and indeed more women than men care, other research has shown that a substantial minority are

men (Green, 1988; Parker, G., 1990; Harris, 1998). As pointed out by Arber and Ginn (1994), because of feminist concern with informal caring, the role of men in informal caring has been ignored. National research and other studies have documented that older women are more likely to be disabled than older men (Townsend, 1979; Qureshi and Walker, 1989). Therefore, where older men care, they are perhaps more likely to care for their spouse. Indeed, the GHS (1990) reported a higher percentage of men than women aged 65 and over were carers (14% and 12% respectively). Large numbers of men do participate in informal caregiving, and many tasks carried out by carers are not necessarily gender related (Neal *et al.*, 1997). Nonetheless, women are more likely to provide personal care (except in caring for a spouse) and where men do give such care they may be perceived as needing more support (Parker 1992). One reason for men's lesser involvement with the provision of personal care may be to avoid any cross-sex taboos, particularly in the care of someone other than a spouse or partner. Ungerson's (1987) study of carers of older people also suggested gender differences in the nature of caring in that men performed tasks with a more organised approach and often likened it to a job, whereas women highlighted the emotional side of care-giving. As discussed, the family and especially women continue to provide the bulk of support to older people in the community. The costs to carers involved in this vital role will now be discussed.

### **2.4.3 The Financial Costs of Informal Care**

Caring can impose great financial burdens (Finch and Groves, 1983; Ungerson, 1987). For some people this may be temporary, but for others such as carers of older people, caring can mean long term poverty. This section of the chapter outlines some of the financial and employment implications of caring. In particular it explores some of the assumptions about family roles and responsibilities assumed by the carers of older people.

Relatively little is known about the real financial consequences of caring for older people over many years. However, in a survey carried out by the Carers National Association (1992), 47% of carers reported financial difficulties since taking on the caring role. Glendinning (1992) in her study on co-resident informal carers of disabled adults (the majority of those receiving care were aged 70 years and older) found that financial losses were commonly experienced. Disability and illness are often accompanied by additional costs, which can be substantial. For example, extra expenditure may be required for special equipment such as a wheelchair, or home adaptations including handrails and/or a stair lift. Regular daily costs include extra heating and laundry, clothing and bedding, particularly necessary for an older person who is doubly incontinent, and other personal items and food, especially if a special diet is needed. The family car may need some adaptation, or taxi fares may stretch household budgets if public transport either cannot be used or is largely unavailable. Money for day care centres, respite care, domiciliary services and sitting services may have to be found. The effects of this for older people and their carers are real and underestimated. Importantly, quality of care is bound to be affected by financial limitations. Despite this, carers' financial contributions appear to be virtually unrecognised in the government benefits system.

A recent survey by Age Concern (1995) reported that half of pensioner households depended on pensions and benefits for at least 75% of their income and that over 1.7 million people aged 60+ were receiving Income Support because of their low income. In addition, social security provision for older people with disabilities and their carers can be considered patchy and inadequate. Most of the available benefits, for example the Disability Living Allowance, of which there are two components (care and mobility) for people under 65, and Attendance Allowance for people aged 65 or over, are aimed at those receiving care. Carers

themselves (under the age of 65) can claim Invalid Care Allowance (ICA) if they spend at least 35 hours per week looking after someone. However, this is one of the lowest social security benefits at only £38.70 a week with an earning limit of £50 (April, 1998). Financial assistance obtainable from the state is restricted in one way or another so that it applies only to some groups of carers and may not help many of the poorest. Furthermore, as no person or profession shoulders a recognised responsibility to inform older people and their carers about the benefit system, many are unaware that they may be entitled to benefits. Age Concern (1995) report that in 1991 up to 33% of eligible pensioners did not claim Income Support. The complexities of the system and the assumption that caring is a family responsibility may deter some people from claiming.

Glendinning (1990) argues that consideration of income and social security needs have been more or less invisible and conspicuously absent from discussions about 'community care'. Policy makers have failed to address issues regarding adequate incomes for carers and how carers can continue to provide community care without some form of impoverishment. Parker has argued: '...the full economic costs (and indeed value) of informal caring remain yet to be calculated' (Parker, G., 1990: 57).

Common assumptions about caring and family relationships work to the disadvantage of carers, in that the family will provide care regardless of personal, social and/or financial costs, and indeed government policy relies upon informal care for older people in the community. Around a third of all informal care to older people is provided by those who are also old (Laczko and Noden, 1993). Many carers are also in paid employment (Baldwin and Parker, 1991). However, little attention has been paid to the numbers of carers who have had to give up paid work or reduce hours because of their caring role. One survey found that

as many as 37% of informal carers of older people thought they might have to give up work or retire early (Phillips, 1993).

The groups most affected by restrictions in employment are women in general (Askham *et al.*, 1992). In particular, Askham *et al.* found gender and marital status of the carer, household composition, relationship of the cared for person and hours of caring to be of relevance, thereby revealing quite a complex picture of the impact of caring on employment. Other work suggests that the impact of caring on employment may be especially severe in early middle age (Lewis and Meredith, 1988). The financial aspects of this can be quite devastating; for example, Joshi (1992) advises that women who give up full-time employment at a later stage in their working lives stand to lose about £12,000 per annum (1990 levels). Parker and Lawton (1992) suggest that male carers lose comparatively more income than women do. Furthermore, the financial costs of caring continue after its cessation. Ex-carers with little or no recent work experience may find it extremely difficult to acquire suitable employment (McLaughlin, 1991).

For those carers in employment, research has shown that caregiving can have adverse effects on their career (Glendinning, 1992). For instance, a lack of training may affect promotion opportunities, and the responsibilities of providing care may force a reduction in working hours. Therefore, carers are at risk of becoming deskilled and losing employment opportunities (Walker and Ahmad, 1994). Many suffer feelings of guilt and divided loyalty to their employer and to their family by needing to take unofficial time off (e.g. Phillips, 1993). In addition, there may be worries associated with balancing the two equitably. Phillips argues '(t)he awareness of eldercare, the stress it can impose on the carer and its effects on their work performance are not acknowledged extensively in the UK' (Phillips,

1993:144). On a more positive note, the new National Carers Strategy announced by the Government in June 1998, is bringing together representatives of industry alongside carers and agents of health and social services in order to achieve more support for carers. It is hoped that more understanding of carers' problems will lead to more carer-friendly workplaces, thereby relieving some of the strain employed carers are under. Recent news released by the Government says it is considering extending the 'new deal' for the unemployed to help carers. In addition, under the forthcoming 'Fairness at Work' legislation carers would be eligible for time off work for family emergencies (Hibbs, 1999).

Caring can not only impose considerable strain on the carer's material resources and employment prospects, it can also have other costs: e.g. psychological costs (Jones and Peters, 1992), social costs (Askham *et al.*, 1992) and health costs (Lewis and Meredith, 1988). These additional costs, in conjunction with the financial strains, may affect the carer's ability to cope and to continue in their caring role. These factors will be discussed in more detail in chapter four.

## **2.5 Conclusion**

This chapter has endeavoured to demonstrate how demographic and political forces have influenced past and present community care policy in relation to older people, and in particular their carers. Gradual changes in the provision of care for older people have over time moved informal carers into the political arena. Hence, it can be argued that it is in the interest of current government policy to advocate better support and more choice for carers. With the gradual recognition of the contribution of carers, support for them has been the focus of different reports and legislation, the most influential being the Griffiths Report (1988), the White Paper entitled *Caring for People* (Cmnd. 849, 1989), the NHS and

Community Care Act (1990) and the more recent Carers Recognition and Services Act (1995).

Care in the community actually means care by the community, which increasingly means care by the family. Arguably, this also puts the onus on individuals to care. Informal carers can therefore be viewed as a vital reserve to be used as care needs increase. The question is whether government objectives, designed to aid carers in their role, are actually translated into more support for carers. It could be argued that carers are encouraged to care for longer with minimal practical and emotional support and very little financial aid. If this is so, there appears to be a mismatch between the policy advocated and actual support to carers. Many carers remain invisible, especially minority ethnic groups. These communities are believed 'to care for their own' (Baxter, 1988), as has been documented by several writers (e.g. Mays, 1983; Patel, 1990; Pharoah and Redmond, 1991; Mehta, 1993). Hence, there is a need for more proactive measures for all carers. Resources, information and support need to be more widely available to carers to absorb some of the social and emotional costs involved in caring for older people in the community. It is hoped that 'Caring about Carers: A National Strategy for Carers' (DOH, 1999) will indeed ensure that carers' concerns will be given a higher profile in all policy development and that their value is properly recognised.

In conclusion, this chapter has concentrated on the ethos and wider debates surrounding community care and carers of older people in general. Britain is a multicultural society and factors that particularly impinge on the lives of older people and their carers from minority ethnic communities will be discussed in the following chapter.

## CHAPTER THREE

### THE ETHNIC DIMENSION IN COMMUNITY CARE

#### 3.1 Introduction

In Chapter Two it was indicated that the vast bulk of existing research concerns carers in general. In contrast, there is little published information on the situation of carers and older people from minority ethnic communities. Britain is a multi-ethnic and multi-cultural society, and black and minority ethnic groups have resided in Britain for over a century. Nevertheless, it is well documented that black minority ethnic groups have not received appropriate, accessible and adequate services to meet their needs (Norman, 1985; Fenton, 1987; McCalman, 1990; Bowling, 1990, 1991; Walker and Ahmad, 1994). In addition, many authors argue that health, social and community service provision is ethnocentric and based on racist assumptions (Cheetham, 1982; Patel, 1990; Williams, 1990; Dominelli, 1991; Bowes and Domokos, 1993; Twigg and Atkin, 1994). Hence, older people and their carers from black minority groups are considered to be marginalised in relation to community care planning and provision (Walker and Ahmad, 1994). Caring experiences may thus be different for minority ethnic groups.

This chapter aims to explore some of the main issues and debates pertaining to carers from minority ethnic communities. It begins by looking at demographic factors relating to black minority ethnic groups and then focuses on the South Asian population who form one of the largest communities in Britain, and who are the subjects in this research (section 3.2). Due to the heterogeneous nature of the South Asian group, the following part of the chapter will tease out some unique patterns of migration, religion and family organisation (section 3.3).

It is hoped this approach will lead to a better understanding of the experiences carers may have. In order to explore this further, section 3.4 of the chapter then concentrates on the debate in health and ethnicity and its implications for carers. The remainder of the chapter (sections 3.5-3.7) deals with issues particularly relating to this group of people in terms of formal service provision and barriers to access, service uptake and the nature of informal care.

### **3.2 General Background Issues Relating to Ethnicity**

Recent estimates suggest there are more than three million people from black and minority ethnic groups living in Britain today (Berthoud *et al.*, 1997). This population is, on average, younger than the white indigenous population (Growing Older, Cmnd. 8173, 1981; OPCS, 1990; Atkin, 1992; Atkin and Rollings, 1993). Five percent of the black and minority ethnic population of Britain is aged 60 and over in contrast to 21% of the white population. However, the numbers of older people from black and minority ethnic groups aged sixty and over have more than doubled in the past ten years (Askham *et al.*, 1995), and the trend for this age group to increase will continue for the foreseeable future (Patel, 1994; Pharoah, 1995). In addition, statistics from the OPCS 1990 have shown that there is a much larger black and minority ethnic population approaching pensionable age (13% are aged 45-59 years). Hence, there will be an increasing number of black and minority ethnic people in older age groups who may have health disability problems (Fenton, 1987). This factor has major implications for the availability of community care provisions to meet the needs of older people from formal and informal sources.

Within the broad category of black and ethnic minority populations, the South Asians constitute the largest single minority group in Britain (Fenton, 1987; Atkin, 1992).

Nonetheless, the South Asians do not form a homogeneous group (Ballard, 1990), and neither do older people from these communities (Boneham, 1989). They may, however, because of their minority ethnic status, experience common problems and needs.

The South Asian demographic profile indicates that older people from this group will increase 3 to 7 times during the next 15 years (Patel, 1994). In order to obtain clear research outcomes it was considered more effective to study two of the largest South Asian communities settling in Britain; those originating from the Gujarat and Punjab regions. Detailed investigation of these subgroups was expected to provide conclusions of wider relevance to other Asian groups of carers. A more general study attempting to consider the whole South Asian community would have required an impracticably large sample to provide representative material.

Most immigration of the Gujarati and Punjabi communities to this country occurred during the 1950s and 1960s with main groups of immigrants originating from India and Pakistan, and during the late 1960s and early 1970s, mainly Gujaratis and Punjabis from East Africa. Migration 'waves' (Norman, 1985) reflect global political, economic and social forces (Williams, 1990). In turn, the nature and timing of these past migrations have influenced the numbers, age-gender structure, spatial distribution, position and life experiences of the Gujaratis and Punjabis in Britain today. Particularly relevant to this research is that differences in migration patterns and numbers may affect gender balances in the different cultural groups. According to Fenton (1987), despite female longevity, the earlier migration of wage earning men to Britain may mean men will outnumber women. This is the reverse of the situation among the white indigenous population and may mean that fewer Gujarati and Punjabi female carers are available to provide care for older people from their

community. This factor is therefore of the utmost importance when exploring the possible future numbers of informal carers, the bulk of whom are women (Green, 1988; GHS, 1990). In order to develop knowledge of experiences of carers, it is important to look at a number of factors. It therefore becomes necessary now to look at migration and other determinants, which will allow more of an insight into the cultures of the two largest South Asian groups.

### **3.3 Similarities and Differences in the Cultural Groups**

This section of this chapter focuses mainly on Gujarati and Punjabi families whose roots are in the Indian subcontinent, but who now live in Britain. Although these families all originated in the same continent, there exists a rich diversity of language, religion, tradition and culture. The different groups enjoy distinct systems of practices, beliefs and relationships (Stopes-Roe and Cochrane, 1990) which will have a bearing on community care provision. In order to gain some insight into the characteristics and experiences of these different communities, three main areas concerning migration, identity and religion, and the family are explored. The first section begins by examining migration patterns and their impact on Gujarati and Punjabi communities in more detail, which might give some idea of support networks available to carers from these two groups.

#### **3.3.1 Migration**

Post-war Britain, especially in the 1950s to 1980s, saw considerable migration from different minority ethnic groups once subject to British rule. Generally speaking, earlier post-war Gujarati and Punjabi migrants were economically motivated male wage earners who came to Britain to find opportunities for themselves and their families. Their arrival took the form of chain migration: migrants in Britain would call over relatives from India who would in turn call other relatives (Ballard and Ballard, 1979; Shaw, 1988; Ballard,

1990). More recent migrations included their dependants such as wives and parents, and Asian refugees en masse from East Africa. Vertovec maintains:

*'The British Asian population therefore developed by way of contrasting modes of migration and from diverse socio-cultural and economic backgrounds'.*

(Vertovec, 1996:78)

Hence, differences in migration patterns, such as those Gujarati and Punjabi groups originating from South Asia, have influenced the period of residence, numbers, age and gender structures, as well as the location of the different groups in Britain today (Williams, 1990; Modood *et al.*, 1994). For instance, certain areas became known as Punjabi locations, such as Southall, west London, and the Leeds Road area of Bradford; or as Gujarati locations, such as Harrow and Hendon in northwest London (Burghart, 1987). Although these migration patterns are not to the same scale in Northamptonshire, similar clusters do exist which will influence community care planning and delivery and thereby the experience of carers.

Importantly, these differences at the point of migration may have influenced the experiences and expectations of the different communities (Berthoud *et al.*, 1997), such as in the provision of both informal care and the availability of formal services in the community. In addition, some groups of migrants will have been able to establish themselves more firmly both nationally and within their locality. Research has shown that many Punjabis have been in Britain for a longer period than other Asian groups, such as Gujaratis (Modood *et al.*, 1994). Not surprisingly, it was found that the proportion of older Punjabi people was greater than for other Asian groups.

Most migration occurred post-war; therefore, it is unlikely that many older members of South Asian groups were born in Britain (Berthoud and Beishon, 1997). The fact that many older people were born outside Britain may have implications for Gujarati and Punjabi older people to access certain benefits such as a right to a pension in older age without the evidence of a birth certificate. In addition, past employment opportunities, especially for women who may not have made the necessary National Insurance contributions, affect pension options and rights, and hence older people and their carers' capacity to provide adequate care. Consequently, some older Asians may need to rely on benefits such as Income Support. However, if white older people do not claim benefits they are entitled to because they are either unaware of them or are deterred by the complexities of the system, then it must be doubly difficult for older Asians (see Chapter 2, section 2.4.3). Again, factors such as these will influence the capacity of carers to provide the range of care to an older person.

Although many of those early migrants from the Asian subcontinent were well qualified, they may have been limited by their level of fluency in English (Robinson, 1990; Modood, 1997). Hence, migration can also affect their opportunity and position in the labour market. Studies have shown that regardless of qualification levels and social background, many Asian migrants were limited to low-paid manual work in industry and the public service (Stopes-Roe and Cochrane, 1990; Modood, 1997). Despite a rise in self-employment amongst migrants, and given differences in Asian groups and amongst men and women, they also had much higher levels of unemployment than the indigenous white population. This difference can be attributed to an existence of racial discrimination in the labour market. For example, a study by Stopes-Roe and Cochrane (1990) reported an unemployment rate of 35.1% for Hindus (mostly Gujarati speaking), and 23.6% for Sikhs

(mostly Punjabi speaking) compared with 19.4% for the white population. Although recent evidence indicates that some minority groups may be getting better jobs, they are still generally doing less well than whites with the same qualifications (Modood, 1997). Therefore, many may remain economically disadvantaged into their old age. Obviously, the language and economic barriers have implications for carers both in terms of their ability to access services and for providing informal care with little money to spare.

Migration patterns may further affect household structure. Many South Asians live together in relatively large households (Henley, 1983a, 1983b; Fenton, 1987; Atkin *et al.*, 1989; Williams, 1990). Recent information from the Fourth National Survey of Ethnic Minorities in Britain shows that older Asians often lived with their sons and daughters (Berthoud and Beishon, 1997). This situation may not have resulted solely through cultural norms but also from economic imperatives; for example where 'sponsored' dependants such as older parents have been reunited with families already established in Britain (Williams, 1990). Nevertheless, it is also important to note that many older Asians are without their families as they have been refused entry to Britain (Walker and Ahmad, 1994). One study found that 26% of older Asians had no family at all in Britain and 31% had no relatives in the neighbourhood (Chevannes, 1991). Therefore, it cannot be assumed that older Asians will have automatic support from their immediate family when needed. Clearly, the composition of different households is crucial when considering culturally appropriate local facilities for older people and/or their carers in service planning and delivery, and housing policy. So far, the discussion has focused on how migration patterns have impinged on Gujarati and Punjabi families' structure, welfare rights and employment opportunities and how these factors may affect the provision of care. The next issue to be explored is the importance of cultural identity in Gujarati and Punjabi communities living in Britain.

### 3.3.2 Identity and Religion

The histories of older Asians are undeniably bound up with Britain's colonial past. Indeed life in India is still influenced by Britain (Blakemore and Boneham, 1994). Since migrating to Britain, many Asians have also experienced the social changes that have taken place over the past three decades. They are therefore very much a part of this past who share similar concerns to the indigenous population (Blakemore and Boneham, 1994). Nonetheless, it is argued that many within the white indigenous population, including health and social care professionals, have viewed Asian people's social lives as inferior and ill adapted in that their habits are harmful to health and need changing (Atkin, 1991). In addition, Asian religious beliefs and cultural practices are seen as '...pathological sources of social problems or mental distress' (Blakemore and Boneham, 1994:78). Such negative views of the Gujarati and Punjabi lifestyle may mean that support services to older people and their carers may not be so readily forthcoming.

It is instructive to remember the circumstances surrounding Asian migrants after their arrival in Britain. Many were viewed and treated with hostility, forcing them to rely on one another for support (Ballard and Ballard, 1979; Shaw, 1988). Naturally, being virtually isolated from the rest of society meant that the Gujarati and Punjabi cultural heritage and values were cherished and preserved. This resulted in the formation of meaningful and self-sufficient networks of relationships capable of maintaining communities (Ballard and Ballard, 1979; Modood *et al.*, 1994; Modood, 1997). Cultural traditions in diet, language, music, social norms, family loyalties and religion were thus retained. Not only is people's region of origin important as a component part of their identity, religion also features very strongly (Modood, 1997). Therefore, attention must also focus on the major religion within Gujarati and Punjabi speaking communities. In Britain the majority of Gujarati speakers

follow the Hindu religion, whereas the majority of Punjabi speakers are of the Sikh religion (e.g. Modood *et al.*, 1994). This is not to deny the immense importance of other minority religious affiliations within these two linguistic groups, such as Muslims; however for the purpose of this section only Gujarati Hindus and Punjabi Sikhs will be referred to, as these constitute the majority groups.

Religion is an important defining characteristic for South Asian people (Beckerlegge, 1991; Modood, 1997; Anwar, 1998; Bhopal, 1998). Vertovec points out:

*'Religion is fundamental to the ways in which people often identify themselves not only in relation to others and to historical circumstances, but also in relation to some deeply believed transcendent reality, ordained code of conduct, and sacred symbols. This-worldly and other-worldly points of reference, as it were, are interposed'.*

(Vertovec, 1990, cited in Vertovec 1996:88)

Religion plays a major role in the identity of both Hindus and Sikhs, unlike the white population in Britain as a whole where there is a growing number of people who have no religious affiliation (Modood, 1997). In addition, religion helps to shape social networks and community organisation (Beckerlegge, 1991; Anwar, 1998). For some women (the main carers), it also prescribes that they continue in the traditions of their ancestors (Bhopal, 1998). Assuming the responsibility to care for one's elders is an example of this.

In times of ill health and feelings of isolation religious beliefs and practices assume greater significance (Henley, 1983b). Hence, an informed understanding of some of the religious and cultural values in Hindus and Sikhs can only aid the provision of good community care to older people and their carers.

Unlike Hinduism, Sikhism recognises the fundamental principle of equality (Singh and Smith, 1985). For example, men and women of all castes may eat together, whereas the Hindu caste system does not allow lower castes to worship or eat with higher castes. Gujarati Hindus, particularly, tend to be vegetarian and do not eat food that has involved taking the life of another living being. Meat is thought of as polluting and eggs are considered a source of life. Sikhism does not prohibit the eating of meat, although some Sikhs will follow the Hindu tradition of vegetarianism (Henley, 1983a, 1983b). In addition to differences in religion and diet, there are differences in dress. Both Hindus and Sikhs believe one should be modest about their bodies and for women it is particularly important to cover their legs and upper body. The traditional female attire for Hindu women is a sari, whereas most Sikh women wear salwar kameez, which is a long tunic with trousers (Henley, 1983a, 1983b). Many male Sikhs (especially older Sikhs) adhere to the five K's: kesh (uncut hair); kanga (comb); kara (steel wrist band); kirpan (sword, today often an imitation sword worn in the kanga); and kaccha (short under-trousers). Indeed, the long hair and unshorn beard are basically the only things which outwardly distinguish the Sikh from other Asians (Singh, 1976). Therefore, the most obvious clothing worn by male Sikhs is the turban to cover their uncut hair. Naturally, being unable to wear a turban would mean that male Sikhs would be unable fully to practise their religion and proclaim their ethnicity. Clearly, all of these religious imperatives need to be respected if health and social workers are to provide good community care.

Retention of culture is important for Gujarati and Punjabi communities living in Britain. Asians in Britain wish to hold on to their cultural identity, including religious following, distinct patterns of social customs and their mother tongue (Anwar, 1998). It is also true to say that sharing one's life with other cultures influences one's own value systems. Hence, at

the same time these families adapt to western norms and values (Anwar, 1998). Therefore, ethnic identities do not remain static. Changes across generations mean that a new form of ethnic identity has apparently emerged (Modood, 1997), and this factor has raised the possibility of some intergenerational conflict (Anwar, 1998). The following section in this chapter explores how changes across generations may affect the family in the following of cultural and religious traditions and its relation to the provision of informal care.

### **3.3.3 Family Organisation and Social Change**

The literature (Stopes-Roe and Cochrane, 1990; Ahmad, 1996; Anwar, 1998) available on family organisation amongst South Asian groups does not present any evidence of significant difference between Gujarati and Punjabi speaking communities. Hence, for the purpose of this section, they will be described as one.

The family unit remains fundamental to most societies. Generally there are two main family types which can be distinguished: the nuclear family mainly consisting of parents and pre-adult children living together; and the joint/extended family which may include several generations with a complex pattern of mutual obligations (Anwar, 1998). Rightly or wrongly, the former structure is more associated with the white indigenous population, whereas the latter is connected more with traditional Asian families. Social and economic circumstances are considered important in determining family organisation in different cultures. The extended family is more visible where personal mobility is limited and where members rely more on one another for aid and support. It is created by descent as well as marriage patterns and as such entails strong family obligations, which play an important part in the lives of individuals. According to Fenton (1987) and Anwar (1998), migration has changed the structures of Asian joint/extended families in Britain. Additionally, there are

pressures for change as well as the wish to maintain the ethos of the traditional family system.

Since migration to Britain, marked differences in values and beliefs have developed between first and second generation Asians (Modood *et al.*, 1994). The values and standards of many older Asians are shaped more by the culture of where they were brought up and less by British influences. The attachment to the family unit, the identity it provides and the social support it supplies, are very strongly valued. Extended family living arrangements have thus traditionally been the norm with families originating from the Asian subcontinent (Blakemore and Boneham, 1994). Indeed, it has been argued that older Asians may feel stigmatised if they are not being cared for in an extended family (Ely and Denney, 1989). Nonetheless, more recent evidence shows a trend towards more nuclear households amongst Asian families (Anwar, 1998). Despite this, it appears that obligatory relationships between parents, children and siblings remain (Bhachu, 1985; Anwar, 1998).

Hierarchies of social obligations relating to kin ties exist in both Asian and white families. Finch and Mason (1993) found that, in the first order after the spouse and other relatives in the same household, white families placed more reliance on daughters; Asian families in contrast looked more to sons for support. In other words the family obligations and normative priorities involved in care-giving lie more with sons and their families in Asian culture. This difference in expectations is demonstrated by the traditional norm for Asian brides fully to join their husbands' families in Asian communities. It is apparent that for Asians it is the nature and pattern of marriage that are important in explaining family social organisation. Traditionally, marriages are often arranged within groups to bind families together, thus extending mutual obligations. In other words it is more a contract between

families than between individuals (Anwar, 1998). In addition, wedded couples do not tend to enjoy an exclusive relationship: marriage is placed within the context of the joint family (Ballard and Ballard, 1979). As such, there may be more of a pressure to ensure that the marriage stays intact.

For the daughter-in-law, marriage means that she is faced with other duties and obligations. For example, the well-being of the family she has married into becomes the priority. In relation to informal caring for older people this means looking after in-laws (although this does not include the provision of personal care to adult males in the family). In addition, structural rules within Asian families include patriarchal authority and respect related to age and sex (Anwar, 1998). Older members of the family therefore retain their power and higher status. Given that daughters-in-law are brought into households with existing family arrangements, it is perhaps understandable that, as reported by Ahmad (1996:58): ‘...conflicts between mothers-in-law and daughters-in-law are legendary’. Naturally, living in an inharmonious environment with an obligation to provide care when needed may result in perceived low levels of morale as well as placing daughters-in-law (normally the carer) at a greater risk of experiencing stress in their daily lives.

Traditional hierarchies and customs, such as those described above, have been disrupted by migration in that older and younger members of Asian families may have competing values and obligations as a result of living in Britain (Walker and Ahmad, 1994; Ahmad, 1996; Bhopal, 1998). Within the home, younger people are taught that their first loyalty is to the family group with little emphasis on personal self-interest, whereas at school they are encouraged to develop as individuals making independent decisions (Ballard and Ballard, 1979). Hence, it has been argued that older generations feel less in control of their families.

They perceive that younger members of the family are threatening traditional cultural values such as family obligations and marriage patterns (Ahmad, 1996), which have led to 'inescapable tensions' (Fenton, 1987: 22). At the same time, the life styles of these younger generations are naturally very different to those of older members. For instance, exposure to European media and values may influence attitudes and religious beliefs, especially for those born and educated in Britain. Younger Asians are no longer restricted to their own circle and therefore their contact with others is more diverse and diffuse. It also means that their social life is less centred on the family and friendships are possible across ethnic groups. However, some of the older generation's fears may be largely unfounded as many young Asians still believe in the merit of joint/extended families and in the system of arranged marriages (Anwar, 1998). In addition, members of the older generation themselves can and do modify cultural traditions in order to fit in with their life in Britain such as some older Punjabis not adhering to dietary regulations (Drury, 1991).

Older Asians, though, are facing new concerns that may affect their status in their community. These include the younger generation's wider knowledge of British society, a more fluent skill in the English language and a possible greater earning potential. The bilingual advantage of younger Gujarati and Punjabi family members may be called upon to deal with formal agencies on behalf of older relatives. Naturally, when this entails sensitive subjects concerning, for instance, health or finances, this may prove to be difficult or embarrassing for all parties concerned. Ahmad (1996) argues that absence of these skills in older people may have an impact on their perceived authority as well as hierarchies of reciprocity and control. There is no doubt that younger Asians, especially those born and raised in Britain, are exposed to a diversity in attitudes, beliefs and values which may consequently mean a diffusion of traditional Asian beliefs and cultural expectations i.e., a

process of acculturation (e.g. Aranda and Knight, 1997). The question is whether these changes will affect patterns of family obligations and informal caring, and, if so, to what extent. The younger British born generations still have a strong sense of duty to the family and its prestige, and still value it for its support and stability (Modood *et al.*, 1994). They are, however, less committed to family members outside their immediate family of siblings, parents and grandparents. In terms of caring for older people it would appear that relations such as frail aunts and uncles are less likely to receive automatic support from younger generations not of their immediate family. As in white families, changes in family and household structure, geographical dispersal and financial pressures mean that it becomes more difficult for extended family networks to provide care to older relatives (Walker and Ahmad, 1994). In addition, it is thought that women (the traditional carers) entering the labour market may be a force in changing Asian traditional reciprocities which may also lead to a renegotiation of gendered responsibilities such as household and caring duties (Bhachu, 1991). However, as pointed out in Chapter 2 (section 2.4.2), this concern has not been realised in white indigenous families, as many women of working age combine the provision of informal care with paid employment.

Clearly, factors explored in the effects of migration, cultural identity and patterns of family organisation have an impact on the provision of care in the community. Older Asians and their carers face many of the same health problems and stresses as populations from other cultural groups. Hence, this next section of the chapter will explore the health of Asians in Britain. Given the limited information on the health of Gujarati and Punjabi communities, for the purpose of this section they will again be largely treated as one group.

### 3.4 Health in Asian Communities

The overall volume of literature on health and ethnicity is quite small (Karmi and McKeigue, 1993). In addition, there is even less available literature on health and older Asian people (Blakemore and Boneham, 1994). Despite a growing interest in this area, the discussion of race and health still does not feature strongly in debates on policy in Britain (Blakemore and Boneham, 1994). Due to the way policies and practices have developed in response to the needs of the indigenous population, there is a lack of a sensitive awareness of some special needs or problems among some Asians (Pearson, 1984). Having said that, there is an accompanying danger that Asians may also be pathologised as a distinct group with stereotypical patterns of health and disease. Indeed, as argued by Atkin and Rollings (1993), research and planning have concentrated largely on specific health problems such as thalassaemia, sickle cell anaemia, rickets, osteomalacia and tuberculosis (Donaldson and Taylor, 1983; Donovan, 1986; Ahmad, 1994; Anionwu, 1994). Although these diseases need specialised services, relatively few people are affected and the focus on more general needs may thus be diverted (Atkin and Rollings, 1993).

Other than for mental health problems, which are less reported (Cochrane and Stopes-Roe 1980) and may be thought of in terms of social dysfunction (Rack, 1982), research has suggested that the incidence of disability is higher among older Asians than for the older white indigenous population. For instance, a study on older Sikh women in Leamington Spa found half of the whole sample and all of those aged over 75 to be suffering from a chronic illness (Boneham, 1989). Another survey on Gujarati male and female older people in North London found them to be more prone to illnesses such as heart disease, diabetes mellitus, cerebro-vascular accidents, asthma and gastro-intestinal disorders than the white indigenous sample (Ebrahim *et al.*, 1991). Although such surveys are increasing in number, as argued

by Atkin and Rollings (1993), there is a dearth of empirical work which probes the relationship between black people's experience of health, illness and disability and community care. Therefore, there is no true understanding of what disability actually means to older people and their carers from black and South Asian communities. Atkin argues:

*'...being black is an important aspect of a person's experience..., and the disadvantage black people face in health, education, housing and employment is well documented'.*  
(Atkin, 1992:54)

Most minority ethnic communities, such as Asian communities, are established in inner city areas and the majority of older black people live in the poorest housing (Baxter, 1988; Mehta, 1993). Urban deprivation has implications for community health and social services that will have to manage provision in areas where Asian communities are not in fact a minority. In addition, the fact that older Asians may have a disability at a younger age than the white indigenous population means that they may need care for a longer period of time. This has the potential to make the experience of caring different in these two groups. The following section of this chapter will now look at some of the main issues and debates in the development and delivery of formal service provision to minority ethnic groups in Britain.

### **3.5 Formal Service Provision to the Ethnic Minority: Policy and Practice**

In the introduction of this chapter, it was stated that black minority ethnic groups have not received appropriate, accessible and/or adequate services to meet their needs. The foregoing sought to explain why they are considered to occupy a marginal position in the health and social service system. Writers have argued that:

*'Racism is agreed to be central to understanding this disadvantage'.*

(Atkin, 1992: 54)

and that:

*'...racism is a deep-rooted social and economic phenomenon in modern society...'*

(Jacobs, 1988: vii)

It is also important to look at how historical and social factors affect the lives of minority ethnic groups. An important consideration in this debate has to be the immigration status of such groups. Successive policies since the British Nationality Act of 1948 have severely restricted British citizenship rights to many individuals from the New Commonwealth such as those originating from the Gujarat and the Punjab. The questioning of these citizenship rights has led to an uncertain status for many individuals in our society where many are viewed as immigrants rather than as citizens. In theory all British citizens should have equal rights and access to services whatever their class, gender, age, race or ethnicity. However, it is contended that racism, both conscious and unconscious, by individuals and institutions, permeates our society and perpetuates racial inequality (Jackson, 1987; Cashmore and Troyna, 1990; Dominelli, 1991; Atkin and Rollings, 1993). Dominelli argues:

*'As a part of this process racism is the fundamental barrier preventing access to opportunity, privilege, power and social justice for the black population.'*

(Dominelli, 1991: viii)

The Race Relations Act, 1976, took positive steps to eliminate unlawful racial discrimination and to promote equality of opportunity. Nonetheless, one assumption in Britain has been that race relations are merely an attempt to regulate community relations. Hence, although:

*'the majority of ethnic minority persons in the country enjoy formal citizenship in law...they are denied equivalence as members of the 'nation'. Thus the institutions of the state and the agents of the state may treat them differently'.*

(Husband, 1996:43)

Such a supposition also has implications for the relationship between ideas of citizenship and equal opportunity in the delivery of statutory services (Cheetham, 1987). In other words, an interpretation which in effect denies basic civil and individual rights to black people does not lead to proactive practice by formal service planners and providers in ensuring that the needs of older people and their carers from such groups are appropriately met. Not surprisingly, it has been argued that both the National Health Service and the social services resembled one another closely in their response to the existence of multi-racial communities and in their progress towards multi-cultural sensitivity (Johnson, 1994). A report by the Association of Directors of Social Services and the Commission for Racial Equality (1978:14) long ago described their response as 'patchy, piecemeal and lacking in strategy'.

At this stage of the chapter it is pertinent to look at some of the dilemmas for service providers and the complexities involved in the pursuit of equality and the policy and practice of service provision to Asian minority groups. Cheetham (1987) argues that the traditional and politically uncontentious official response has been that since individuals from minority ethnic groups share universal human needs then these needs should be met by identical services-i.e. a colour-blind approach. This, it was claimed, should ensure equal treatment. Nevertheless, such an approach ignores the very real question as to whether the service that is provided is in practice available and appropriate to all members of minority ethnic communities. Ely and Denney (1989) contend that such a policy may appear to be

non-discriminatory but in effect, it excludes black people, such as Asian people, from its provisions. For instance, meals on wheels help many carers to continue caring but may often be culturally inappropriate in terms of the non-availability of vegetarian Indian or Halal meals, and therefore this service may not be accessible to many Asians. In addition, there has perhaps existed a 'chicken and egg' situation in that poor uptake of services has been perceived as a lack of special need, thereby promoting a vicious circle of non-provision of an appropriate service.

The above situation has further been compounded by a stereotypical belief that Asian people provide for their own and therefore require less in the form of mainstream service provision. In contrast to this complacent view, Cheetham (1987) argues that it can be said that, with no clear government guidelines, service providers have had to face several dilemmas:

- Whether to treat black minority groups differently in order to reduce their inequalities;
- Whether privileged treatment to black minority groups, such as Gujaratis and Punjabis, can be politically viable in society if similarly disadvantaged white indigenous people feel and express a great sense of injustice;
- Whether such groups would feel they were being stigmatised and their lifestyles pathologised and seen as different.

Atkin (1992) contends that the idea that black people have 'special needs' can be seen as an example of racism. It is no wonder that such dilemmas have led to an ideology of

integration, such as a model by which black minority communities are said to have equal opportunities and whereby cultural diversity is accepted and tolerated. The practice of cultural diversity professes to educate care professionals to respond to cultural barriers in a more positive and sensitive way, such as an awareness of specific and different needs. Nonetheless, in reality, the practice of cultural diversity can be said to be sorely lacking. Writers argue that the needs have merely been reframed and 'slotted' into mainstream service provision which is still fundamentally eurocentric (Ahmed, 1992; Atkin, 1992; Kwhali, 1994), and grounded in inappropriate generalisations (Atkin, 1991). For instance, Kwhali mentions services established for specific ethnic groups run by white majority providers (Kwhali, 1994).

As indicated earlier, the policy guidance following the NHS and Community Care Act, 1990, constitutes a positive initiative to combat racial discrimination in service delivery. Nevertheless, few health authorities and social service departments have actually followed up their declaration of intent with any clear strategy to respond to the needs of a multicultural population (Atkin and Rollings, 1993). In a survey of 92 social service departments, it was reported that even where a committed equal opportunities policy did exist, it did not automatically lead to success (Butt, 1994). Butt describes simplistic ethnic monitoring classifications with no reference to an individual's language or religion. An example of this is where one council spent a tremendous amount of effort and money adapting services to meet the needs of people of the Hindu religion where in fact the community was predominantly Muslim (Baxter, 1988)! Butt (1994) also found that many black workers employed by service providers felt they were confined to being experts in black issues, thereby being denied opportunities for expertise in social work practice.

The organisational, ideological and practical changes heralded by the NHS and Community Care Act, 1990, appear to promise a new way forward. In Paragraph 2.9 of 'Caring for People' (Cmnd. 849, 1989) it was stated:

*'The Government recognises that people from different cultural backgrounds may have particular care needs and problems. Minority communities may have different concepts of community care and it is important that service providers are sensitive to these variations. Good community care will take account of the circumstances of minority communities and will be planned in consultation with them'.*

Such a statement emphasises user views and choice and it is in this context that the needs of older people and their carers from black minority ethnic groups such as Asian communities can be actively incorporated into service planning and provision. However, as argued by Patel (1994), although minority communities are now properly recognised and the need to provide specific services legitimised, the policy statement may still prove to be mere rhetoric. Service planners will indeed require significant practical changes and shifts in policy to overcome past barriers in the provision of accessible and appropriate services to older members and their carers in minority ethnic communities, and meet their community care responsibilities.

Having concentrated on the stereotypes that influence service provision, this chapter now debates the extent to which services are utilised. In particular it focuses on barriers to service uptake experienced by South Asian people.

### **3.5.1 Barriers to Access and Uptake of Service Provision**

Research has shown that many services are not being utilised by minority ethnic groups

(McCalman, 1990) leading to a conclusion that barriers exist. There are a number of main barriers to the access and uptake of services. These include the appropriateness of formal provision, communication and cultural factors. Each of these three main barriers will now be discussed in turn.

In the previous section of this chapter, it was indicated that Asian minority groups share universal human needs. Many minority groups within the indigenous population experience barriers to service uptake that are created by insensitive service provision. People with learning disabilities, the physically disabled and those unable to see or hear are examples of this. Indeed, all community care service users can be regarded as minority groups of the general population. However, black disabled people are doubly absent from many of the available resources (Begum, 1992).

A review of the literature has shown two main reasons for the invisibility of older Asian people and their carers within statutory service provision (Baxter, 1988; Franklyn, 1992; Patel, 1994; Walker and Ahmad, 1994). Firstly, this group has, overall, been regarded as numerically insignificant resulting in non-existent or poorly planned services to meet its needs. Secondly, as indicated earlier, the myth that the Asian community 'takes care of its own' has meant that community service providers have assumed no need to include them in the development of services. The assumption was that if services were required, then the Asian community would come forward to claim them (Kalsi and Constantinedes, 1989). Recent policy initiatives, for example Caring for People (Cmnd. 849, 1989), do however place a duty on authorities to identify needs in their community and endeavour to meet them. Nevertheless, other problems to effective service uptake by the Asian community and other minority ethnic groups may exist. These include language and communication

barriers, both in written and spoken English, compounded by a lack of information regarding the range and availability of services.

One of the more familiar barriers to service uptake is that of language (Atkin and Rollings, 1993). Service practitioners view language as a principal barrier; consequently, the use of interpreters as well as providing information on services and welfare benefits in Asian languages is regarded as good practice. However, this approach to solving the problem is rather simplistic and often approached in an unsystematic manner. Consider firstly the use of interpreters. As found by the Commission for Racial Equality (1992) and Pharoah (1993), often people are encouraged to bring along their own interpreter, for example family members, rather than the onus being on service providers to ensure that a trained person skilled in their particular language is available. In effect, this means that the responsibility lies with the client to understand, and not on the service provider to assure that messages are fully comprehended. In most situations, this can be regarded as wholly inappropriate. In addition, the use of family members may result in difficulties with confidentiality as well as potentially embarrassing situations for the person seeking help. Situations involving conflicts of interest also arise, for instance where a carer asks for a break but the care recipient, for whom the carer is interpreting, is against the idea of any respite care.

There may also be problems with the understanding of medical terminology and advice. This latter objection also applies to the use of bilingual staff who do not have professional interpreting skills. Difficulties other than linguistic still exist even when trained community interpreters have been employed. Lee (1992) cites personal communication with a community worker who highlighted two key problems:

- finding interpreters with sufficient knowledge of legislation, specialities and services;
- class differences between the translator and the person for whom they were interpreting influencing the consultation and its outcome.

Given these points, there is some danger in suggesting that difficulties can be easily overcome by the use of an interpreter. Service providers will need to consider the very real tension between providing objectivity via interpreters and the subjective and inappropriate private use of family and friends.

In addition, there are problems regarding access to written information and welfare benefits. Many Asians have a different first language from English and older Asian people, in particular women, have not had the opportunity to learn English. Some older Asian people and their carers are therefore not likely to speak, write and understand English (e.g. Bowling, 1990; Donaldson and Johnson, 1990). This has great implications for the understanding of health and social care information and advice (Leisten and Richardson, 1996). This difficulty is further complicated by evidence which shows they may not be literate in their own language (Dowd, 1993 and personal communication from Dostiyo, Asian Women and Girls organisation). It can be argued that service providers have tried to overcome language problems by producing appropriate literature in the different languages and have thereby met their responsibilities. Nonetheless, if people are unable to read both English and any translated material and therefore remain unaware of available services, the consequences of these combined factors are that barriers to basic entitlements and services remain a reality. Therefore, even information leaflets may not be an effective means to service uptake, such as in the need for welfare and other benefits.

Health and social services are trying to overcome communication barriers by the use of audio tapes. It is hoped that this method of imparting information will reduce non-awareness of services and benefits available. For instance, many carers miss out on benefits such as attendance allowance because they are not aware of its existence (Baxter, 1988). Older Asian people in particular may also be unaware of the correct level of pension they may be entitled to. As a result, household income may be appreciably lower in comparison to older white indigenous people (Blakemore and Boneham, 1994). Such a factor may also be viewed as a barrier to accessing services such as home-helps and respite care that may be charged for. As argued by Jadeja and Singh (1993), the very low socio-economic position of older Asians who may have had little opportunity to work and build state, occupational and private pensions means that they have to maintain themselves on low financial resources. In addition, this may be reflected in their ability to pay for, and receive community services. Language problems and a lack of knowledge among the Asian community may therefore not be the only issues that relate to service uptake and appropriate service provision.

There are additional factors, which help to prevent Asian groups from taking up services available, and thus affect their experience of caring. These concern the inappropriateness of provision in general, such as services which are culturally insensitive.

Service practitioners' lack of knowledge about cultural and religious beliefs and social norms create particular barriers. Much of the care available is culturally insensitive (Cornwell, 1992) and:

*'Too often statutory agencies assume that apart from dietary needs this client group have the same needs as white elderly people'.*

(Franklyn, 1992: v)

The misunderstanding of the specific needs of older Asian people and their carers can be witnessed across the whole sphere of service provision. Examples include the only available religious care in hospitals being for Christian faiths (Walker and Ahmad, 1994); gender imperatives such as personal care not carried out by the opposite sex (e.g. Ahmad, 1996); and only bedbaths provided which may be considered unclean (George, 1993). In addition there are concerns regarding day centres where no one can speak the same language or no other black people attend the centre (Keeble, 1985; Wilson, 1992a) and where there is no provision for separate areas for females (Pearson, 1994). This latter factor is particularly important when discussing women's health (Pharoah and Redmond, 1991).

More generally, there are problems with care workers trying to force Asian names into the British naming system. Examples include the religious middle name of Singh used as the surname, thereby missing out the correct surname and misrepresenting Asian names and forms of address, which may lead to treatments being delayed or even given to the wrong person (Henley and Clayton, 1982). Such examples of cultural insensitivity negatively affect take-up of statutory services by older Asian people and their carers, who may perceive that services are not meant for them (Keeble, 1985; Walker and Ahmad, 1994). One way to overcome low service uptake is to raise levels of expectation of older Asian people and their carers by increasing the understanding of all statutory service providers. There is some evidence of a shift in attitudes on a national level, for example the Patient's Charter (Department of Health, 1991) and work done by the Commission for Racial Equality which has prepared codes of practice on the quality of care for minority ethnic groups. Nonetheless, it appears that many people from minority ethnic communities may still be unaware of their rights. One recent study found that only 3.9% of the sample were aware of the purpose of the aforementioned Patient's Charter (Richardson *et al.*, 1994).

Although there is a mixed picture of provision right across health, social and community services, there are signs of change and new local initiatives to lower barriers to accessing care, for instance, specific staffing appropriate to a particular local population (Pharoah and Redmond, 1991), and efforts to educate care workers in the different cultural and religious beliefs, values and norms. Evidence has shown that, where agencies have made efforts to provide translated materials, interpreters and Asian community workers, contact and use of services increase significantly (George, 1993). In addition, the NHS and Community Care Act, 1990, does recognise that minority ethnic groups' care needs should be fully considered in community care planning and provision. Its policy and practice guidance emphasises user involvement and choice alongside needs-led services and consideration of race, religion, culture and language in the attempt to enhance access to services by minority ethnic communities. Furthermore, the Carers (Recognition and Services) Act, 1995, gives heavily involved carers, of any culture, the right to an individual assessment of their needs. However, it is important to remember that there is a danger in assuming that merely because service providers may be culturally aware and services are offered that needs are actually being met.

### **3.6 Knowledge and Use of Services by Asian Groups**

An earlier section in this chapter (section 3.2) indicated that increasing numbers of older Asian people will inevitably lead to greater demands for adequate and culturally sensitive health, community and social services. Awareness of community-based health and social services by older Asian people and their carers appears to be limited although they all have a direct impact on the life of carers. Therefore, it now becomes pertinent to examine the experiences of older Asian people and their carers within statutory service provision, such as services that are used and services, which although offered, are used infrequently. The

use of health and community-based services, such as the General Practitioner (GP), community nursing services and additional community health services (e.g. occupational therapists) will be discussed first. This will be followed by the uptake of social service provision such as use of home-helps, meals-on-wheels, day centres and respite services.

One service, which is well subscribed to by the Asian community, is that of their General Practitioner (Pharoah, 1993, 1995). Many Asians believe their GP knows what is best for them and highly regard his/her decision (Bould, 1990). In contrast to this, Fenton (1987) suggests that one reason for black minority older people's high consultation rates is that they experience poor health earlier in late middle age than do white older people. Attributable factors for this may be structural disadvantages and discrimination in areas such as poor housing and employment opportunities (Atkin and Rollings, 1993), and the effects of migration and changing lifestyles (Norman, 1985). Other reasons for high consultation rates include worries about language barriers, especially for women (Fenton, 1987). Although the majority of Asian people are registered with a GP (Fenton, 1987), service providers appear to ignore their presence when formulating specific policy and planning objectives. The GP could be considered the most obvious point of contact for this group, yet research has shown that GP information regarding specific local services groups is frequently limited and incorrect (Pharoah, 1995). GPs were found to have generally little liaison with social services and health authorities and made few referrals to other agencies (Wilson, 1992b). In addition, language problems have been found to prevent effective communication between people from minority ethnic groups and their GP (Richardson *et al.*, 1994). Naturally, this further affects the quality of any necessary treatment and the need for other service provision.

Many black people have a holistic and integrated view towards health care in the community. In contrast to this, the British mainstream model divides services into separate parts such as home care, day care, counselling, information etc. (Pearson, 1994). This may help to explain why fewer older Asian people and their carers are aware of provisions such as community nursing (Atkin *et al.*, 1989). Research has shown that community nursing services are barely used by Asian groups (Norman, 1985, Cameron *et al.*, 1989). Cameron *et al.* (1988) suggest that reasons for this include ethnocentric services geared towards white norms and the 'gate-keeping' role of GPs who have the power to refer patients to specific services. Moreover, community nurses themselves often stereotyped Asian patients as having low pain thresholds, complaining needlessly of 'trivial health problems' and being uncooperative (Cameron *et al.*, 1989). Nevertheless, many older Asians are interested in the use of a community nurse once they become aware of such a provision, for example a bath nurse, although Asian men expressed a preference for a male to carry out such intimate tasks (Atkin *et al.*, 1989).

Research on the use of other community health services by the Asian community is limited. However McCalman (1990), in her study of informal carers, found they had some knowledge of, and did use, podiatry services, a particularly important resource for older people. Yet, Asian carers and their relatives had no awareness of occupational therapy, psychiatric community nursing, health visiting, physiotherapy and continence advisory services. This means that many older Asian people and their carers are not informed of pertinent services available to them, which might otherwise help to provide a better quality of support.

The limited knowledge of social service provisions is equally well documented (Atkin and Rollings, 1993). Again, this clearly has implications for the appropriateness and effectiveness of such support to Asian communities. Although low take-up of services does not reflect low need, their take-up is probably related to how sensitive and responsive the service is to those who may need it. Some general concerns amongst the Asian community regarding home-help, meals-on-wheels, day centres and respite services will now be briefly discussed.

Atkin *et al.* (1989) found that, once Asian people understood the home-help service, they were prepared to use it. However, the lack of Asian home-helps was a major reservation (Jowell *et al.*, 1990; McCalman, 1990; Dowd, 1993), and concerns were expressed about shopping for the right kinds of food and doing jobs around the house as they would expect. Similarly, doubts over the use of meals-on-wheels have been raised. Mehta (1993) indicates that religious taboos such as in methods of preparation and handling of food may be a barrier for the acceptance of such a service. Gunaratnam (1993) found that many Asians thought the service was totally inappropriate as it was centred around white norms such as the scant provision of vegan or Halal meat meals. Dowd (1993) suggested that the service would be welcomed if it provided Asian food, and one enterprising local authority (London Borough of Newham) selected local Asian restaurants to deliver hot meals on a regular basis (Pearson, 1994).

Although there is a shortage of culturally appropriate day centre places (George, 1993), this service may be of increasing importance to those Asians aged between 51-59 years suffering from a chronic illness. In a study of older Sikh women (Boneham, 1989), found that the women drawn from a day centre for older women formed a younger population than

would normally be associated with the white indigenous equivalent. Unfortunately, negative experiences such as unacceptable food and a fear of the possibility of being the only Asian there combine to reduce a willingness to use such a service (Jowell *et al.*, 1990). Bould (1990) described how some older Asian people felt out of place because of inappropriate activities in a predominantly white day centre, such as a reminiscence project, for which one older Asian was unable to share the memories. In addition, one reason for the negligible take-up of day centre places by older Asian people is the explicit racism towards them by white older people attending such centres (Patel, 1990; Askham *et al.*, 1995). This concern affects both older people themselves and their carers and does not encourage such minority ethnic groups to make use of this facility. Francis (1993) describes a more culturally sensitive and flexible alternative, for instance older people being cared for in an appropriate formal carer's own home. Although this form of care may be suitable for some, it does not provide wider social contact with others, which is so important in overcoming feelings of isolation.

There is also little evidence about the knowledge and use of respite services. Yet, relief care which reflects religious and cultural preferences is a top priority for carers (Bould, 1990). Other work describes how Asian families either knew nothing about this provision or knew so little that they were unwilling to consider it (Ellahi and Hatfield, 1992; Dostiyo, 1993). Farrah (1986) studying black minority groups, concluded that it was the least known community service. It is hoped that the recent publicity surrounding the promise of £140 million to enable carers to take a break (Hibbs, 1999) will, firstly enlighten carers from minority ethnic communities that this service is available. Secondly, it is hoped that the money is intended for culturally appropriate respite provision to all carers, thereby allowing for an equitable service provision.

So far, it has been shown that there are many concerns regarding the use of statutory services. Social service agencies are trying to overcome problems of non-awareness of services by employing Asian link-workers to advise and inform Asian communities (Askham *et al.*, 1995). Despite these initiatives, service uptake does not just depend upon knowledge. One respondent in Bould's study on Asian carers in Leicester (1990:18) argued that one reason for low service uptake was that: 'Asians don't come forward to ask for services. They don't like to question or challenge professionals, but quietly accept what they are told is available'. There may be an element of truth in this. Mehta (1993) talks about pride and non acceptance of 'handouts'. Nonetheless, such statements can only be true if it were certain that Asian communities were aware of all services that were available. In addition, it does not mean that Asians should accept a second class choice and neither does it accord with the fears and reservations expressed above, or explain why black voluntary groups developed and initiated basic services as a result of shortfalls or inappropriate statutory service provision (Blakemore, 1985; Gunaratnam, 1993). Walker and Ahmad (1994: 643) argue:

*'...basic care services for the majority of Asian and black people needing care - not to mention 'choice' - will be provided only if Asian and black community groups and voluntary organisations manage to provide them'.*

The next section in this chapter will thus briefly discuss the position of voluntary organisations.

### **3.6.1 Asian Voluntary and Self-help Groups**

Traditional voluntary agencies have tended to neglect the needs of black older people (Patel, 1990). Many have evolved with the needs of white users as their main focus (Reading, 1994). Hence, in a survey by Walker and Ahmad (1994), it was reported that general

community-wide voluntary services were not found to be ethnically sensitive. More recently, government policy in the form of a mixed provision of care calls for making the best possible use of voluntary service provision. In addition, it is argued that changes implied in the contract economy provide the context in which the care needs of minority ethnic communities can be addressed (Ahmad and Atkin, 1996). These two factors can be seen as a positive move for the maintenance and growth of Asian voluntary organisations. As such, it can be argued that these organisations are a vital resource by acting as catalysts for social change. Yet, whether this potential can be realised as an important political force still needs to be determined (Reading, 1994). Although the various voluntary and self-help groups can be seen as mainly local developments in tune with a multi-cultural and multi-ethnic society, these very resources on which older Asian people and their carers rely are now possibly under threat. The contracting out of services may at the same time have negative effects. The pressure of a tight and limited budget for voluntary service activities may mean that some small voluntary groups will be overlooked and therefore disadvantaged further, unless local authority service policy sets out to prevent this from happening.

Kwhali (1994) argues that service providers have often directed black people to underfunded voluntary groups. The statutory provision of appropriate services is not just good practice; all people in Britain are entitled to it, and the failure to provide adequate and suitable services constitutes a failure to meet professional responsibilities.

This section of the chapter has explored issues concerning the knowledge and use of some of the formal service provision to older people and their carers from Asian communities. It now becomes pertinent to look at how the response of health and social services has affected the experience of informal caregiving in these groups.

### **3.7 Informal Care and Support**

The General Household Survey (1990) estimated that 6.8 million people in Britain are informal carers (see Chapter 2, section 2.4.2). However, the data do not indicate how many of these are from black minority ethnic groups or indeed how many are from the Asian community and caring for an older person. Any other information on this subject tends to be based on local surveys and research (McCalman, 1990; Gunaratnam, 1993; Walker and Ahmad, 1994). Therefore, there is little general quantitative and qualitative information available on the experience of informal care and in terms of perceived levels of stress and morale among Asian groups.

Despite the greater visibility of carers in general in policy debate, in Asian communities caring has only recently been acknowledged as an issue where the needs of its carers have thus far attracted little attention (e.g. Baxter, 1988). Asian carers are even more marginalised than older Asian people; unknown to the statutory services but at the same time relied on by them. They therefore remain 'invisible' (Walker and Ahmad, 1994: 642).

Although many Asians consider it their duty to care for older relatives (Baxter, 1988; Dostiyo, 1993), stereotyping Asian communities as having a special capacity to look after their own has resulted in service providers taking Asian carers of older people for granted. Indeed, needs of older Asian people are only considered as needs if they are not being met by relatives (Walker and Ahmad, 1994). In addition, stereotyping Asian families as doing all the caring has had the effect of discouraging service providers from not only offering services in the first place but also changing a service to fit their different needs (Ely and Denney, 1989).

As with other informal caring networks across Britain, research has shown that the locus of care in Asian families is often the immediate family, with the care usually being carried out by the women (Bould, 1990; McCalman, 1990). In Asian tradition, sons are considered responsible for the care of older parents (Henley, 1983b). Hence, men may see themselves as the carer, although they may not carry out any caring activities. Therefore, women carers in Asian communities who assume the more concrete role of caring may find it extremely difficult to be acknowledged as the actual carer. In addition, underlying and compounding the situation of many Asian women are not only the divisive effects of migration resulting in cultural alienation, language problems and lack of knowledge about local services, but also direct and indirect racism and discrimination. Clearly, factors such as these may affect feelings of stress and perceived levels of morale. Earlier research on depression among South Asian women in Bristol by Fenton and Sadiq (1993) has shown that the degree of loneliness and isolation experienced is in many cases due to racial hostility. This may profoundly affect female carers' daily lives, such as fears to go out alone, enforced immobility being unable to use public transport unaccompanied, and if older themselves a likelihood of ill health disabling their movements even further. As succinctly put by Dowd (1993: 18):

*'Compound this with ageing, language difficulties and having to cope without a spouse who was your link with the outside world and you have an isolated and insecure person'.*

Younger Asian women carers often have small children but have to work to enhance their family income thereby predisposing them to further physical and emotional stress. Recent research in Bristol has shown that, to an overwhelming extent, all the 179 Asian women in their 20s and 30s spoke of extreme tiredness and feelings of exhaustion from their domestic

responsibilities, a fatigue compounded for those who were employed (West and Pilgrim, 1995). Research by Fenton and Sadiq (1993), on Asian women in Bristol suffering from depression, reported how cultural norms for Asian women differ significantly from those that influence women in western societies. Asian tradition sets great importance on family and community relationships; family disputes leading to a breakdown in these relationships may threaten the roles by which people define themselves. This can result in immense emotional and mental upset. Hence, evidence for stress exists in both Asian and western households. Naturally the feelings of stress within families can also be experienced by older people and their carers (e.g. Williams, 1990; Blakemore and Boneham, 1994).

One study found that one of the major problems for Asian carers was the lack of finance (Bould, 1990). Many older Asian people unable to obtain a state pension were totally dependent on their families and, whilst many were receiving benefits, they had only done so after a battle or a lengthy period unaware of their entitlement. Other problems which may particularly affect older Asian people and carers include poor housing such as old accommodation in inner cities, and areas of deprivation which lack basic amenities such as hot running water, efficient heating systems as well as possible overcrowding (Williams, 1990). McCalman (1990) and Gunaratnam (1993) found that, where housing conditions were bad, they became a central concern and '...this seemed to take precedence over their caring role' (McCalman, 1990: 47).

With the introduction of the Carers (Recognition and Services) Act, 1995 in April 1996, many carers are legitimately entitled to service provision in their own right when requested by them. Nonetheless, the onus is on carers to ask the local authority to carry out an assessment and, for carers from minority ethnic communities, this means they must first be

made aware that services for carers exist. Given the fact that lack of knowledge is a barrier to obtaining even basic services, it seems unlikely that many Asian carers will be aware of this legislation. Indeed, the legislation does not directly affect the accessibility of services to Asian carers. Gunaratnam argues:

*'Asian carers have always provided not only care in the community but also care by the community in the face of inaccessible services',*

and ...

*'...radical and imaginative changes are needed to enable services to meet the wide-ranging and specific needs of carers...'*

(Gunaratnam 1993: 122)

The physical, emotional and financial impacts of caring for an older person in the community affect many carers, irrespective of their ethnic origin. Nonetheless, for Asian carers, multiple disadvantages in society have exacerbated the problems experienced. Their particular needs remain unrecognised.

### **3.8 Conclusion**

This chapter has concerned itself with the ethnic dimension within community care policy. Community care objectives have been determined in the series of government reports discussed in the preceding chapter. Yet, it is only over the last decade that debates on community care have come to realise the potential significance of ethnicity in formulating policy (Audit Commission, 1986; Williams, 1990). Nevertheless, neither the Audit Commission Report (1986), nor the Griffiths Report (1988), make any reference to specific provision for people from minority ethnic communities. Although the resulting NHS and Community Care Act, 1990, and Carers (Recognition and Services) Act, 1995, do not

isolate and highlight race aspects, guidance following this new legislation does offer local authorities the opportunity to change this 'colour-blind' situation and positively incorporate race equality principles and practice into their community care implementation. This can be achieved by recognising the particular care needs of minority ethnic groups.

In order to look at the experience of caring in different cultural groups in more detail, this research has focused on older people and their carers from the South Asian community, who form the largest single minority group in Britain. Previously thought to be numerically insignificant, the proportion of older people from this group is expected to increase significantly (Patel, 1994). One further important reason for concentrating on this population is the stereotypical assumptions about extended family networks providing full support to older family members. Hence, the debates on community care in this chapter have explored the invisibility of older people and their carers from the South Asian community that has been compounded by racism and other barriers.

In order to disentangle specific cultural factors in community care provision, comparisons with the white community as well as between Gujaratis and Punjabis have been made. Pertinent issues regarding migration, identity and social organisation have been explored. Intergenerational differences in attitudes and beliefs have also been shown to have an impact on Asian family systems of obligation and reciprocity. Naturally, these factors may have an impact on future caregiving for older people. Older people with no close kin able to care informally are likely to be more isolated and even more marginalised. Carers of older people who are themselves old may not receive the level of support from family members they might have once expected. At the same time their age and lack of knowledge may preclude them from receiving what little support is available to them.

The gaps in knowledge about ethnic differences in the experience of caring, and the lack of understanding of informal care in minority ethnic communities, means that they have not shared in the recognition afforded to older people and their carers from the wider community. In addition, a lack of ethnic monitoring in terms of language and religion by public and voluntary service providers make analysis of community care uptake difficult. All these factors combined point to a need for further research into the experience of caring in multi-ethnic Britain.

The literature contained within this and the previous chapter (Chapter Two) have indicated some of the strains of informally caring for an older person. The following chapter (Chapter Four) therefore looks at how carers may be socially and psychologically affected by their caring responsibilities.

# CHAPTER FOUR

## PSYCHOSOCIAL IMPACT OF CARING ON INFORMAL CARERS

### 4.1 Introduction

The development of community care policies in Britain over the last twenty years has created a heightened recognition that significant responsibilities for care of older people lie with informal carers. This gradual shift in emphasis to care by the community has brought more clearly to the surface the fact that informal carers incur financial, physical, social and psychological costs (Cantor, 1983; Parker, G., 1990; Twigg, 1992; Thoits, 1995; McKee *et al.*, 1997). Research on the impact of caring has described the daily grind of caring, the disruption to normal life and the accompanying burdens it imposes (Gilhooly, 1984; Deimling and Bass, 1986; Anderson, 1987; Arber and Ginn, 1990; Smith, S., 1993; Smith, 1994; Twigg and Atkin, 1994; Williams *et al.*, 1995). These factors have led to many studies attempting to associate some effects of care-giving responsibilities with stress (Stoller and Pugliesi, 1989; Jones and Peters, 1992; McCarty, 1996). More recently, however, the emphasis when studying stress and caring has been on how individuals cope successfully with their caring role. The importance of mediating factors such as social support and the personal resources, which people draw upon when coping with difficulties, can only add to the understanding of stress and ultimately how to better support carers from different cultural groups.

This chapter begins by exploring the general notion of stress and its manifestation within a caring role (section 4.2). It then discusses the inter-relationship between stress, stressors and

stressful life events. The impact of caring on carer stress in terms of the different aspects of care is explored in detail. Also included in this chapter are the more positive experiences related to the caring role (section 4.3). This is followed by a discussion of how individuals cope with their caring responsibilities by reviewing personal coping resources, styles and strategies (section 4.4). Finally, available social support to carers and its importance in ameliorating the effects of stress and enhancing coping ability is examined (section 4.5).

## **4.2 Stress and Caring**

Over the past fifteen to twenty years there has been a large body of research on the psychosocial aspects of the experience of carers in providing informal care (Fengler and Goodrich, 1979; Cantor, 1983; Gilhooly, 1984; Zarit, 1986; Quine and Charnley, 1987; Nolan and Grant, 1989; Stoller and Pugliesi, 1989; Lawton *et al.*, 1989; Jones and Peters, 1992; Fink, 1995; McCarty, 1996). Most of this research has been on the demands on the carer and the corresponding strain that caring can impose. Studies have shown that carers' social and family lives have suffered and that some informal carers experience stress or emotional strain as a result of their caring responsibilities (e.g.: Cantor, 1983; Lewis and Meredith, 1988; Russell *et al.*, 1989; Jones and Peters, 1992; Matson, 1994; Cossette *et al.*, 1995). Worry, anxiety, fatigue, depression and poor health are factors associated with carer stress. Since the emotional and physical health of carers is important if only on a pragmatic level, and since stress has been found to be prevalent in carers, it is useful at this point briefly to consider the notion of stress itself.

### **4.2.1 Stress, Stressors and Stressful Life Events**

Stress is a multi-faceted concept and is described as a human reaction to difficult life circumstances which involves physiological, psychological and social processes (Sarafino,

1990). In addition, it is an everyday idea talked about by everyone (Selye, 1983) and its concept has a long history (Selye, 1956; Holmes and Rahe, 1967; Brown and Harris, 1978; Rutter, 1981; Thoits, 1995). Yet, the notion of stress also lacks any agreed upon definition:

*'...it is understood by very few, and even by those few in totally contradictory ways...'*  
(Rutter, 1981:323)

Explanations for the variations and contradictions in definition can be reflected by the different theoretical approaches (biological, medical, sociological and psychological). Stress, from a biological and/or medical aspect, focuses on the body's defence mechanisms, which entail certain physiological responses to changes in the environment such as heat and other stimuli. How people react to this is depicted in Selye's General Adaptation Syndrome (1956), which describes the three stages of response to stress: an initial alarm reaction, stage of resistance, and finally exhaustion. The sociological perspective is more concerned with individual's responses to changes in social circumstances such as support, income, marital relations and an individual's general well-being (e.g. Holmes and Rahe, 1967, Jenkins *et al.*, 1981; Brown and Andrews, 1986; Fink, 1995). Psychological approaches to stress (transactional/interactional models) emphasise more the individual's cognitive appraisals of a demanding situation and their response to stress using personal coping resources (Wheaton, 1983; Holahan and Moos, 1985; Thoits, 1995; McKee *et al.*, 1997).

In relation to this study on informal carers, it is a combination of the psychological and the sociological aspects of stress that is of particular relevance. The psychosocial model takes into account changes in social circumstances and allows for important individual differences in their response and appraisal of the caring role to be explored.

In the context of this study on carers, it is not only how adopting a caring role may affect perceived morale in carers (e.g. Palmore and Luikart, 1972), but also how it may impinge on an individual's ability to cope with a change in their circumstances that becomes important. In order to understand how these changes affect individual carers, it becomes pertinent to distinguish between stressors and stress. Stressors are those factors that produce the tension or stress, and stress is the mismatch between these demands and individual capacities. Thus, stressors are perceived as excessive internal or external demands on a person's ability to cope (Rutter, 1981; Lazarus and Folkman, 1986; Thoits, 1986; Edwards and Cooper, 1988; Thoits, 1995). Pearson and Vaughan's (1988) division of stressors into three categories is directly relevant here. Firstly, intrapersonal stressors, for example concern over a change in the health of a family member. Secondly, Pearson and Vaughan identify interpersonal stressors occurring between one or more other people, which could include role changes within a relationship and the need for care. Finally, extrapersonal stressors relate to factors, which occur outside the individual. A reduced income or migration can be examples of this.

Naturally, response to stressors varies from person to person and therefore different events mean different things to different people. Certain stimuli or events only become stressful when individuals perceive them as such: for example, the need to carry out certain caring tasks seen as a burden by some and not by others. Therefore, much depends on individual subjective interpretation (Grant and Nolan, 1993); past experience (e.g. McCarty, 1996); personality (Braithwaite, 1990; Watkins *et al.*, 1991); and the standards by which carers are evaluated, such as values, expectations and abilities (Edwards and Cooper, 1988). A line from Shakespeare's Hamlet, Prince of Denmark (Act II: 449) seems quite relevant here:

*'...for there is nothing either good or bad, but thinking makes it so'.*

Although most people encounter stressful life events at some time within their life, which may entail some change to their daily routine, the vast majority do not develop emotional disorders (Kessler *et al.*, 1985). Nonetheless, it is important to note a distinction between acute stressors, such as life events which require behavioural adjustment (e.g. divorce), and chronic stressors which are recurrent or persistent demands which need readjustments over time (Thoits, 1995). Caring for an older person provides an example of the latter.

Research has shown that long-term changes, such as caring, are usually debilitating (Avison and Turner, 1988). In addition, it has been shown that providing extended and extensive support is physically and emotionally draining (Aneshensel *et al.*, 1993). In specific relation to carer responsibilities the stress process can be said to be driven by two major types of stressors (Pearlin *et al.*, 1990; Aneshensel *et al.*, 1993). Primary stressors constitute the demands and tasks of basic daily care, such as personal maintenance of the older person (for example bathing and dressing), and instrumental tasks, such as paying bills, organising appointments etc. These responsibilities have to be met on a regular basis (Aneshensel *et al.*, 1993). However, secondary stressors, although not task related, compound the caregiving role. Secondary stressors commonly experienced by carers include financial problems, a disrupted social and family life and friction with employment (Pearlin *et al.*, 1990). These stressors develop over time in the carer's life. Other secondary stressors relate to subjective feelings of self, for example a loss of control, self doubt and a feeling of being 'trapped' (Bould, 1990; Nolan *et al.*, 1990; Aneshensel *et al.*, 1993). All these combine to generate a source of stress for carers, whatever their culture or background.

Other research which pertains to this study on white indigenous and South Asian informal carers has shown that ongoing strains are more prevalent in lower status, disadvantaged

groups (e.g. Brown and Harris, 1978; McLeod and Kessler, 1990; Turner *et al.*, 1995), whose members are particularly vulnerable to stressors (Thoits, 1995). At the same time, men and women appear to be more sensitive to different subsets of stressors. For instance, men seem to be more susceptible to financial and job-related stressors, whereas women may be more negatively affected by events which happen to their loved ones (Kessler and McLeod, 1984; Turner and Avison, 1989; Conger *et al.*, 1993). Hence, it is important to note that a carer's status, as well as their gender, will influence their experience and level of stress.

#### **4.2.2 The Impact of Caring on Carer Stress**

Becoming a carer involves adjustment and change in the lifestyle of the person providing the care. Caring takes place in a relationship and this in itself gives an added meaning to the tasks carried out by carers (Richardson *et al.*, 1989). Many carers carry out their responsibilities of caring with a great sense of love, loyalty and generosity. Before individuals assumed the carer role, they were a spouse/partner, a daughter, son or other family member, a friend or neighbour, often in a mutually caring and reciprocal relationship. Although people continue to be the spouse, daughter etc., the relationship itself undergoes a change and it may become less mutual and more unilateral. As succinctly described by Smith, J. (1993): informal caring has no rules; it may well be a long-term commitment in a one-way relationship with possibly no expectation of reciprocal care or reward. It is perhaps therefore not surprising that sometimes the care willingly given to a loved one becomes a source of ongoing difficulty and stress.

The individual circumstances of carers vary enormously and it is not clear which factors impinge the most on the experience of stress in different people. As indicated in section 4.2,

much depends on the individual perception of events. Nonetheless: '(t)he point that caregiving is stressful is now well established' (Zarit, 1989: 147). More important though, is what can help carers to lessen their experience of stress.

In recent years, many studies on informal care have described the caring responsibilities individuals adopt as 'a hassle', as demanding and as a burden (e.g., Gilhooly, 1984; Zarit, 1986; Equal Opportunities Commission, 1988; Arber and Ginn, 1990; Watkins *et al.*, 1991; Smith, 1994). It is accepted that there are many dimensions of stress and burden and their antecedents and that the relationship between them is complex (Zarit, 1989). Nevertheless, previous studies have shown that there are general adverse effects associated with caring that are suggestive of stress. These include reduced economic and employment opportunities, a disrupted social and family life and poor emotional and physical health (Lewis and Meredith, 1988; Nolan *et al.*, 1990; Parker, G., 1990, Noden and Laczko, 1993; Phillips, 1993). Some of the studies that relate to these aspects are now explored.

It has been reported that some people who work and care for an older relative find it a struggle to combine the two roles (Lewis and Meredith, 1988; Glendinning, 1992). Carers have been found to suffer from a loss of employment opportunities as well as poor concentration, fatigue and high levels of stress (Noden and Laczko, 1993). Relatively few studies of stress and employment in carers of older people have been carried out. However, a qualitative study by Phillips (1993) on 23 employees caring for a person aged 60 or over for at least 10 hours a week looked into the difficulties of balancing their employment with caring. All the carers interviewed noted the stress they experienced in trying to provide adequate care as well as holding down a job. Caring was found to affect work performance, hours worked, and career opportunities. Carers also expressed a need for more flexibility in

their workplace, the lack of which contributed to various feelings of guilt connected to caring and working. For six of the carers, such feelings of guilt were considered to influence their high levels of stress.

The findings regarding the experience of stress reported in this small exploratory study do, however, need to be approached with some caution. Importantly, it is not apparent how the level of stress in carers was determined. Neither does it report what the levels of stress actually were, making any true comparison with future studies on people who work and care for older people impossible. In addition, it does not appear to take into account other factors which may contribute to the carers' experience of stress such as the fact that many of the carers (number unspecified) also had younger adults or children who lived with them. Nonetheless, the study does highlight factors that were shown to be of concern to those who both work and care for an older person and thus has implications for both employers and policy makers.

Other dominant factors associated with stress are the effects of caring on carers' social and family life. A large study by Jones and Peters (1992) of carers of older people reported that over one quarter in their sample of 256 carers felt that caring had detrimentally affected their social life. The more dependent the older people the more the carers were restricted. The maintenance of regular social activities proved difficult. In addition, carers co-residing with the older person reported that a lack of privacy at home reduced their ability to entertain others. Jones and Peters further found that some carers (albeit a minority) felt that their family life had suffered. Some considered that caring had also possibly caused actual damage to their family lives. Although most of the carers in this sample were women (n=201, 79%), the study does not describe whether any of the remaining male carers felt

similarly limited in their social life. As pointed out by Fenton *et al.* (1995), an over-representation of women interviewees means that one has to be careful in drawing conclusions from the whole sample and one cannot do this without examining gender differences.

In relation to carers' views on their social life, it also becomes important to look at how carers viewed the psychological effects of caring. It was found that almost one third of the carers (n=73, 29%) suffered from affective disorders such as anxiety, and over one tenth (n=29, 11%) reported suffering from depression. Although the study took into account residency and relationship of daughters, it again does not report how male carers come into this equation. Additionally the study does not detail which particular measure was used to support this finding, other than by comparison with psychiatric opinion, making true comparison with future studies on anxiety and depression on carers impossible. Nonetheless, Jones and Peters' (1992) work does suggest that carers' social lives can be enhanced by the availability of regular and planned relief care. Again, a solution to a possible source of stress for carers is in the hands of community care planners. Therefore, services and future policies should also be oriented towards the needs of carers and their families and not just the older person requiring care.

The provision of respite care may also help the general health of carers, which is important in that it may affect their capacity to care. A total of 68 (27%) carers in the Jones and Peters' study perceived that caring had negative effects on their own health. Spackman (1991) points out that because the concept of health is both complex and difficult to measure and people have a different tolerance level of health problems, it is one's own perception of health that is important. The findings of the study by Jones and Peters (1992) suggest that

the more disabled the older person, the more this negatively affected the carer's health. Unfortunately, the study does not take into account other factors such as socio-economic variables, which may also influence self-assessed health (Fenton *et al.* 1995). In addition it appears that almost a half of the carers were aged 45-64 years (n=123) and two tenths were aged 75 years and over (n=52). It is known that health deteriorates with age; hence some carers will experience health problems related to their age (Spackman, 1991), rather than as a direct result of caring. Nonetheless, the perceived health status of carers may indeed influence their capacity to care.

Although carers do suffer from health problems, it is difficult to establish that caring actually causes ill health. Nevertheless, the link between caring and emotional problems appears to be much clearer than the connection between caring and physical health problems (Spackman, 1991). Consequently, research has tended to concentrate on the assessment of emotional distress in carers. A detailed survey carried out under the auspices of the Association of Crossroads Care Attendant Schemes between 1979 and 1980 reported high levels of perceived physical and psychological stress being put on carers (Swarbrick and Davison, 1990). With this association, only carers of disabled individuals who were perceived by the co-ordinator to be under considerable stress were in receipt of their services. A postal questionnaire was used to ask objective questions relating to the person receiving care and the carer him/herself in terms of age, disability, length of care given etc., as well as subjective questions regarding the carer's health. It was directed to 50 carers receiving the support of the Crossroads Care Attendant Scheme, of which 35 (70%) responded. One half of those being cared for informally were aged 61 years and above. As reported by Swarbrick and Davison (1990) many of the carers were themselves at an age at which they may expect to have increasing health problems of their own. Nonetheless, this

study highlights that, if carers are to carry on caring, they should be provided with regular support and relief.

In none of the studies above has the level of stress in carers been quantified. Other research has used objective measures to overcome this gap. One of the largest studies available was carried out by Nolan and Grant (1989), who used the Malaise Inventory to measure stress in 554 carers of adults and children belonging to the Carers National Association. Their report revealed very high stress levels. The mean malaise score for the whole sample was 8.97 of which 81% had a score of 5 and above (indicating a feeling of stress outside the normal range) with 60% of carers reporting a score of 7 and above. Characteristics of the sample of co-resident carers (n=522) included the relationship of the carer to the dependant, age of carer and dependency factors. The data did not, however, present analyses of the stress scores controlling for age, gender, ethnicity, relationship to the person receiving care, residency, length of care, dependency needs etc. Therefore it is not clear which factors may influence these very high stress levels and which carer groups they may affect. The research was carried out by the inclusion of a postal questionnaire with a Carers National Association newsletter. There are three reasons for exercising caution in generalising from the results. Firstly, there is the fact that carers were self-selected and therefore defined themselves as carers. Secondly, carers completed the measure themselves. Even though the Malaise Inventory was chosen for its simplicity, the approach used means that it could at times have been completed indiscriminately which would affect the results. A final problem concerns the very high stress score obtained in the research. It may be that only those carers who felt stressed were motivated to fill in the questionnaire (initially 2050 questionnaires were forwarded and quantitative analysis was carried out on 554 from a total of 726 that were returned). On the other hand, it would be more disturbing to think that returned

questionnaires came from a lower end of stress scores and those suffering even higher levels of stress would not have had the time to complete the questionnaire and not return it.

Research carried out by Quine and Charnley (1987), who also employed the Malaise Inventory to measure stress on 226 carers of older people, reported a mean malaise score of only 3.86. Here, interviewees were asked both objective questions about the care they provided in addition to subjective questions about their perceived health. However, of the 226 carers, 175 (77%) were also caring for an older person in receipt of social service provision, which may have had a positive affect on the carers' malaise scores. In addition, 71 (31%) of the carers reported scores ranging from 5 to 16, indicating that they indeed felt stressed in their caring role. The study did control for residency and found that the mean malaise score rose marginally to 3.91 for those living in the same household compared to 3.83 for carers living elsewhere. In this study, therefore, living with the older person or elsewhere did not appear to contribute substantially to the experience of stress. However, the mean malaise score indicated that carers felt stressed when they did not perceive themselves to be in good health ( $\mu=6.56$ ); when carers had experienced recent adverse life events ( $\mu=5.78$ ); and when carers themselves felt high levels of anxiety ( $\mu=5.91$ ). Dependency needs of the older person were also examined in this study. Results showed that where personal and physical help was required carers were found to have a mean stress score of 5 and above. Behaviour problems in the older person were also reported as stressful, with the mean malaise score ranging from 5.39 to 6.82.

This study shows that certain aspects of caring for older people, even with the support from social service agencies, may contribute to the experience of stress in carers. However, the research did not control for carer age, gender, ethnicity, length of care or relationship of the

carer to the older person. Nor did it detail the different stress scores for those carer groups caring for an older person in receipt of social services and those looking after someone with no receipt of social services. Again, it is difficult to determine which particular factors influence stress levels and which carer groups they affect.

The above carer studies show the variation in the experience and levels of stress in general aspects of caring suggested to be associated with stress. Naturally, the individual circumstances of carers will also be different. In order to understand further what carers may find stressful, one first needs to look at caring tasks. Informal carers of older people carry out a whole range of caring activities, from minor assistance to continuous round the clock support (Atkinson, 1992). Sources and nature of stresses on carers of older people can be classified into four main categories: personal/practical; behavioural; intrapersonal/interpersonal; social/cultural. These are examined below.

#### **4.2.3 Personal/Practical Aspects of Care**

The kind of tasks carers carry out naturally varies according to the nature and extent of disability of the older person requiring care. Nevertheless, the 'daily grind' of looking after another person (Parker, G., 1990), and the repetitiveness of tasks (Anderson, 1987) have been well documented. Much of the care provided is essential to maintaining that person in the community and therefore carers of older people will need to respond to various demands, such as providing physical and nursing care for general daily activities (Atkinson and McHaffie, 1992).

It has been noted that carers experience a level of physical exertion far above that experienced by other people in their daily lives (Parker, G., 1990). Activities of personal

care often involve heavy or awkward work, such as lifting an older person up and down stairs, on and off a commode or bedpan, or in and out of a bed, bath or wheelchair (Atkinson, 1992). Indeed, the literature shows that the physical tasks of caring can be tiring, restricting and even dangerous, and that lifting is a frequent cause of injury (Richardson *et al.*, 1989). Perhaps, not surprisingly, Sadler (1990) reports that, from a large survey of 790 carers, as many as 56% had experienced back and muscle strains, fatigue, heart and blood pressure problems. However, some of these problems, in particular back problems, are common amongst the general population: therefore it can be suggested that some carers would have had these problems anyway (e.g. Spackman, 1991). Nonetheless, many of the tasks informal carers are often expected to do are carried out on their own without proper training, whereas elsewhere they would be carried out by nurses who are trained and work in pairs. The literature available, although limited, does suggest that the experiences of Asian carers are similar to those of white carers (Ahmad and Atkin, 1996). The frequent need to provide physical support is experienced by white indigenous and Asian carers alike, who express the need for assistance with such tasks (e.g. McCalman, 1990).

Furthermore, according to Richardson *et al.* (1989) and Goldstein and Rivers (1995), other tasks carried out by informal carers increasingly involve specialised skills normally associated with professional nurses. For example, carers have responsibility for medication, giving injections, the management of incontinence such as fitting a catheter (Sadler, 1990), or tending to pressure sores. These are intimate tasks which require knowledge and skill, and, some of which by normal standards may be considered distasteful or taboo, especially for South Asian carers where it is not considered acceptable to have personal care carried out by someone of a different sex (George, 1993). Having to receive such care can be considered both embarrassing and traumatic to the older person, who may in return resent

the need for such activities, thereby creating an atmosphere of tension in the dyadic relationship.

It is not possible to generalise with regard to the physical and personal caring activities found to be stressful to individual carers. It has, though, been suggested that the physical demands of caring are not perceived as stressful until the carers themselves do not feel in good physical health (Nolan *et al.*, 1990). As indicated above, many carers do not perceive themselves as experiencing good health. However, added to this is the further need to carry out extra housework, shopping, the cooking of special or different meals and, perhaps, feeding the older person. Feeding in particular may not only mean extra laundry and washing of the person being fed, it may also be emotionally upsetting, particularly when the cared for person has difficulty in swallowing and is likely to choke (Atkinson, 1992). There are other physical caring commitments, which have the further effect of constraining much of the carer's life. For example, tasks may need to be carried out immediately or are time bound; therefore, the carer is often on call and unable to control the timing for tasks (Arber and Ginn, 1990). Many of these tasks are carried out daily, each week and for a number of years with the chance of change being quite remote (Smith, J., 1993).

In the public mind, it has been easy to recognise tasks such as lifting, dressing and toileting as caring (Twigg and Atkin, 1994). For some carers the personal/physical elements of caring may be stressful; however it is apparent that the behavioural aspects of caring also constitute a significant portion of the burden of care (Perring *et al.*, 1990; Sinclair, 1990; Twigg and Atkin, 1994). These include aggressive behaviour, wandering about and forgetfulness, all of which have been regarded by carers as primary stressors.

#### 4.2.4 Behavioural Aspects of Care

In this category, the type of care given is less obvious than the personal/physical care described above. Much of the literature on the behaviour of older people, which might constitute a stressor, concerns older people with a mental health problem, for example a dementia. Alzheimer's disease is one of the most common forms of a dementia which exhibits itself as a chronic confusional state (Fraser, 1987), and which has been estimated to affect 2.1% of people aged 65-69 years, rising to 17.7% of people over the age of 80 years (Kay and Bergman, 1980). However, according to Perring *et al.* (1990), the responsibilities of carers caring for people with mental problems is much less researched, and in relation to minority ethnic carers it is non-existent (Atkin and Rollings, 1993). Nonetheless, where material does exist it does show that dealing with the behaviour of older people with a dementia can be quite difficult for carers, and in many cases poses more problems than caring for an older person with a physical disability such as that caused by a 'stroke' (Gilhooly, 1984).

Care for dementia sufferers also often includes a lot of personal and physical care. In addition, it means that carers' lives are more constrained by needing to provide supervision on a 24-hour basis. Major difficulties for carers of confused older people include unsafe acts such as 'wandering', forgetting to light the gas etc., repeatedly asking the same questions, night disturbance causing loss of sleep, coping with noisy or aggressive behaviour and apathy by failing to respond or even recognise the carer's name (Sinclair, 1990). All of these factors can constitute a source of stress for the carer. However, it is not only the behaviour of older people with a chronic confusional state that can cause difficulties for carers. Lucid older people who require support may also pose problems for carers. Qureshi and Walker (1989), in their study of older people and their families, describe the frustrations for both

older people and their carers as an older person's independence declines. Some older people react to their situation by refusing some aids and carer support; others react by calling for constant attention and by placing 'illegitimate demands' on their carer. Further, parents may be unwilling to follow their adult child's instructions necessary for their care. As corroborated by Qureshi and Walker (1989), Lewis and Meredith (1988) argued that attention-seeking behaviour by the older parent might negatively affect their relationship. This situation could provide a potential source of stress for carers.

Primary stressors such as those discussed above may result in the development of secondary stressors that emerge as problems as the caring for an older person continues through time. The following sections explore what may constitute secondary stressors for carers of older people.

#### **4.2.5 Intrapersonal/Interpersonal Aspects of Caring**

Carers do not necessarily volunteer to care for an older relative or friend and caring may be seen more as an aspect of duty than of love (Pitkeathley, 1992). Carers therefore differ in their response to their roles. One consideration is that many carers may not possess the predispositional characteristics for caring as would formal carers, for example nurses who specialise in the care of older people. Carer characteristics can be a main consideration in the observation of psychological distress: '(t)hose who have been habitual worriers will be more distressed as carers' (Watkins *et al.*, 1991:27). In addition, those carers who need to provide high levels of care may feel overwhelmed by their caring role, which can negatively affect feelings of self-esteem; hence a perceived 'loss of self' may result as a consequence (Noonan and Tennstedt, 1997).

The sense of being responsible is common to all caregiving situations, particularly in relation to mental health problems. Many carers also assume responsibility for the conduct of the person receiving care (Perring *et al.*, 1990). Nolan *et al.*, (1990) found in their survey of members of the Carers National Association, that the most important factor implicated in psychological malaise was the nature of the carer's response to their role. For instance, malaise is most likely to occur when the carer feels out of control, worries about the caregiving and feels guilty about the situation. Further specific interpersonal stressors concern caring for an older person where fears for the future and of loss may be of greater importance (Sinclair, 1990). For an older person caring for a partner, experiencing feelings of helplessness may be overwhelming. Here, caring is more likely to be the focus of their lives and more often associated with companionship and intimacy. The loss of this partnership may lead to feelings of loneliness, anticipation of bereavement and finally widowhood (Wenger, 1990). The enormity of how these emotional fears and anxieties may affect an older spouse who cares can be demonstrated by the high score the death of a spouse receives in the Holmes-Rahe Social Adjustment Scale (Holmes and Rahe, 1967).

Feeling close to the older person requiring care may be a precursor to assuming the role of carer. Nevertheless, caring for an older person may negatively affect the emotional basis on which the relationship is built (Sinclair, 1990). Matthews (1979) described an atmosphere of tension in the home as the older parent requiring care was struggling to hold on to sources of power within the family. In her study of daughters caring for their older mother Fisher (1986) observed that power is not simply reversed and may involve a protracted process of negotiation, which can result in a negative change in their relationship. Such tensions may be exacerbated for South Asian carers looking after their older aged parent or in-law. Not only do the old retain their authority (Stopes-Roe and Cochrane, 1990), but older women in

particular assume a considerable amount of prestige, especially in relation to the control of a mother-in-law over a daughter-in-law (Blakemore and Boneham, 1994) who may often be the main carer.

Problems such as these are likely to produce a conflicting mixture of emotions: for example, feelings of resentment towards the older person; feelings of guilt from feeling resentful, and yet at the same time feelings of pity that one could or should do more. Such emotions about caring for an older person can therefore result in a feeling that one has lost control over the situation, and '...unwittingly become captive of an unwanted role' (Aneshensel *et al.*, 1993:55).

As well as a feeling of being trapped and negative feelings about self, other secondary stressors commonly experienced by carers of older people include feelings of isolation brought about by the constriction of social and leisure activities. Carers also face conflicts of loyalties and family tension resulting in role overload and role ambiguity. These other potential variables in the stress process are now explored.

#### **4.2.6 Social/Cultural Aspects of Caring**

Although carers are a heterogeneous group, research on both white indigenous and Asian carers shows that the locus of care is often with female family members (McCalman, 1990; Parker, G., 1990; Sadler, 1990; Ahmad and Atkin, 1996). The general literature on caring has highlighted the loneliness and sense of isolation experienced (Fengler and Goodrich 1979; McCalman, 1990). However, female Asian carers in particular, because of communication difficulties, fear of a hostile outside world and direct racism, suffer extreme isolation (Atkin and Rollings, 1993). Bould's (1990) study of Asian carers showed that

many women felt 'trapped within four walls' and that over half spoke of experiencing depression. Balarajan and Raleigh (1995) write of the high suicide rate in women from the Indian subcontinent.

The feeling of isolation is very similar for men who care for their disabled wife who feel equally lonely and alone in their lives, unable to talk to friends and with dreams of retirement and future plans abandoned (Smith, 1994). Additionally, any strains associated with caregiving will affect the family as a unit (Fink, 1995). Unlike the day-to-day living, as described above, the whole family is affected by constraints on making career changes, moving house and the ability to plan for the future. For younger carers, spending time away from their own family and thereby neglecting other family responsibilities was of considerable concern. Lewis and Meredith (1988) similarly found that many daughters who cared needed to balance not only their responsibilities for their family and the person being cared for, but also their obligations to their employer. A BBC 2 documentary entitled 'A Double Life' (1993) following the life of three carers termed this the 'sandwich generation'. However Lewis and Meredith, (1988) suggest that stress arises less from conflict among competing loyalties than from the carers' sense that they had to take full responsibility both for the caring tasks and for any effects caring might have on family life. As well as 'role overload' Jones and Peters (1992) showed in their survey of 256 carers that many had found their family life had suffered, they had little social life, they felt lonely and rarely had a break.

The incidence and impact of the sources and nature of the stresses on carers do vary with the context in which they occur (Sinclair, 1990). Although evidence is equivocal, other more tangible factors associated with potential stressors for carers include the gender of the

carer (Wenger, 1990), the health of the carer (Spackman, 1991), and whether or not the carer and the supported person co-reside (Fink, 1995). Less tangible aspects of caring which may have an impact on carers are their age and gender (Jones and Peters, 1992), characteristics of the person requiring support (Lawton *et al.*, 1989), lack of knowledge in the caring role (Russell *et al.*, 1989; McCalman, 1990; Watkins *et al.*, 1991), and the onset of the disability in the supported person (Parker, 1992; Twigg, 1992).

Exactly which particular factors involved in caring impact on levels of stress in carers is not clearly understood. There is perhaps not one specific factor that a carer finds stressful, but rather an overlapping of several of the aspects of providing care outlined above. At the same time much depends on the individual's perception of events and situations. Hence, carers in similar circumstances experience and exhibit different levels of stress. These individual differences in carers also account for the fact that there are positive aspects to caring.

#### **4.3 Positive Aspects of Caring**

So far, this chapter has described the tasks performed by carers and the impact of caring on individual carers as a burden and as being a potential stressor. Nevertheless, caring for an older person in the community has its obvious advantages. It allows an older person to stay within familiar surroundings and benefit from regular help and support. Caring is also often based on reciprocity (Motenko, 1989; Harris, 1998) and is a means of returning the love and care individuals have previously enjoyed. Many carers may also derive undoubted satisfaction from diverse sources associated with caring (Lewis and Meredith, 1988; Grant and Nolan 1993; Salvage, 1995; Kramer, 1997), and this may in turn constitute a valuable coping resource (Summers, 1988). Indeed, other work suggests that caring may provide an opportunity ultimately to find meaning in life (Farran, 1997).

Recent evidence has shown that satisfaction derived from the caring role can co-exist with high levels of stress and strain (Grant and Nolan, 1993). Grant and Nolan identified different sources of reward and satisfaction in the caring relationship. Analysis of the qualitative data obtained from a survey of members of the Carers National Association revealed several categories of satisfaction derived from the interpersonal dynamics between carers and the supported person. These included the act of giving to the supported person; maintaining his or her dignity and self-esteem; reciprocity; expression of appreciation, especially if it came from the cared-for person; and nurturing his or her basic needs. Furthermore, the carers themselves experienced a direct gain through caring. At the most fundamental level it was suggested that:

*'...caring meets basic psychic needs for protection from negative self-perceptions such as guilt or the desire to feel wanted or needed...'*

(Grant and Nolan, 1993:153)

Other carers spoke of benefiting from learning new skills and experiencing new personal challenges in coping with the caring role. Interestingly though, satisfaction with caring was not significantly associated with the gender of the carer. Also, reported satisfaction was not significantly related to the age group of the carer or the supported person. Nor was it significantly associated with the length of care given, intensity of care, nature of the disability or amount of assistance required. Such findings are important in furthering the understanding of the challenges facing carers. They may also help community care workers to use interventions that can enhance carer adaptation and morale.

More recently, the debate on caring has moved the focus away from carers towards those who require support. The disability movement argues that community care policy in effect

works to divert more help away from disabled people. Furthermore, disabled people do not ask for care, they want control over their own lives (Wood, 1991). Related to this discussion is a point made by Buchanan and Middleton (1994:67) who succinctly state that: '(t)o have someone 'in your charge' is to be 'in charge' of someone'. Clearly, there is a need for the individual empowerment of disabled people. However, as argued by Parker (1993b) displacing the need for carers would not actually serve the needs of frail older people or others with a chronic illness or disability. Nevertheless, the current critique of caregiving does highlight the importance of both individuals in a dyadic relationship. It is therefore vital that methods for identifying and assessing satisfactions for both the carer and the supported are found. Given that this research concentrates mainly on carers, ideas about stress adaptation, coping strategies and coping resources need to be examined. As outlined earlier, it is still not clear which aspects of caring may be the most stressful and how such stress might be alleviated: i.e., how best to cope, or why it is that some people cope and others do not. Therefore, the concept of coping and coping with caring will now be explored.

#### **4.4 Coping with Caring**

The importance of the individual's perception of what is stressful to them has already been highlighted. As suggested by Cox (1978):

*'stress may be said to arise when there is an imbalance between the perceived demand and the person's perception of his capability to meet that demand. It is essential to realise that the important balance or imbalance is not between demand and actual capability, but between perceived demand and perceived capability. What is important for man is his cognitive appraisal of the potentially stressful situation and of his ability to cope'.*

(Cox, 1978:18)

The ability to cope may of course depend on the individual's sense of personal control, which can have the effect of reducing psychological disturbance and physical illness in addition to buffering any exposure to negative aspects of stress (Thoits, 1995). In relation to caring for an older person, it has been proposed that it is the carer's subjective interpretation of the predicament which is an important factor in mediating the degree of stress experienced (Deimling and Bass, 1986). Hence, much research has focused on how individuals assess their internal coping resources and select appropriate coping strategies (Edwards and Cooper, 1988; Lazarus, 1993). Resources used effectively can be considered as 'crutches' with which to continue in the caring role (Braithwaite, 1990). Internal coping mechanisms which may help people to cope with stressful situations include cognitions, perceptions and behaviours that are used as mediators to counteract stressful stimuli and avoid being harmed, and:

*'...overt and covert behaviours that are taken to reduce or eliminate psychological distress or stressful conditions.'*

(Fleishman, 1984:229)

Early research on coping viewed coping as more of a personal trait. In other words, an individual would be expected to display a constant coping behaviour across changing situations. Hence, it was assumed that a particular coping trait would predict how a person would cope in most circumstances (Lazarus, 1992). Such an approach ignores contextual influences on different situations and does not explain coping inconsistencies over time and across encounters (Lazarus, 1993). Over the years, a number of ways have been developed to classify coping strategies (Ray *et al.*, 1982). However, most approaches make the distinction between coping strategies which are either active in nature, for example by

facing up to the situation, and strategies which involve reducing stress by avoiding the problem (Holahan and Moos, 1987). Folkman and Lazarus (1980) who identify two primary coping strategies offer another definition: problem-focused and emotion-focused responses. A problem-focused approach involves a specific action or response designed to manage and modify a difficult situation, whereas an emotion-focused response approach includes efforts to manage and regulate emotional distress caused by a difficult situation. Although emotion-focused strategies may also be active in nature, for example busying oneself, this behaviour can be considered as avoidance of the source of stress.

Another typology is offered by Pearlin *et al.* (1990) who differentiate between three functions of coping: management of a possibly stressful situation; management of the meaning of the situation, thereby creating a more congenial perception of one's situation; and responses which neither alter nor change the situation or perceptions of it. The objective is not to avoid stress, it is rather a means of managing the stress reaction. This latter response appears to be particularly relevant to this particular study of older people and their carers because, as caring may continue for some years, the 'threat' or stress becomes a part of one's life. What is important here is how the carer satisfactorily manages his/her own life together with that of the caregiving role. This means effectively and realistically dealing with one's feelings and actions regarding a possible source of stress. Here, it is the older person requiring care. A related typology is offered by Billings and Moos (1981) who have suggested that coping strategies may take the form of active-behavioural responses (overt action), active-cognitive strategies (active efforts to appraise the problem), and avoidance strategies (e.g. either ignore the situation or drink, eat, smoke more in an attempt to lessen the tension).

From the different typologies of coping processes one can see there is no agreed upon classification of coping strategies and behaviours. Perhaps, more importantly, research on the influence of coping responses on adjustment has shown that effective coping strategies do vary according to the individual and to the situation (Pearlin and Schooler, 1978; Folkman and Lazarus, 1980). This means that both situational demands (objective) and the individual's response (subjective) to that demand need to be addressed. According to Pearlin and Schooler (1978), Billings and Moos (1981) and Braithwaite (1990), studies have shown that effective coping responses tend to be more active and problem-focused rather than passive, avoidant or non-confronting, the latter having been found to be positively associated with anxiety and burden in carer research (Matson, 1994). Nevertheless, other research has found that avoidance coping may be adaptive where life situations cannot be improved (Collins *et al.*, 1983). In addition, avoidance coping through passivity and acceptance may be a satisfactory coping mechanism for carers, especially when supporting an older person with an incurable degenerative disease (Strong, 1984). This therefore indicates that problem-focused coping may be used more in situations that are seen as controllable, whereas emotion-focused coping is likely to be used when demands are appraised as uncontrollable. However, Strong's work also indicated that cultural background was an influencing factor in both the interpretation of the situation and the subsequent coping strategies. In her study on carers of older family members in an American Indian and a white sample, she found that one main difference was that white carers sought to control the situation, whereas American Indians were more passively forbearing. Hence, white carers tended to use an active coping strategy and American Indians used more of an avoidance mechanism. Other work also suggests that differences in carers from different cultural backgrounds may exist. For example, social values emphasise the importance of interpersonal harmony in people from an Eastern culture-i.e. an avoidance

of confrontation. Conversely, in the Western culture, stress is placed on personal independence and assertive action (Shaw *et al.*, 1997). Consequently, coping styles may also differ in carers with different traditional backgrounds.

Previous research also shows that problem-focused coping varies across situations, whereas emotion-focused coping is fairly consistent. Thus, Lazarus (1993) more recently suggests that a two-level model of coping could fit with earlier work on coping as a personality trait. In other words, because problem-focused coping is so variable, it may be influenced by contextual factors, and because emotion-focused coping strategies are relatively stable, it may be one's personality that affects coping mechanisms. This may also indicate that carers from different backgrounds have different values and beliefs that may influence coping behaviour. Clearly, there needs to be more research into this area to further our understanding of both dispositional and context-specific behaviours in coping.

A study of women carers identified three types of coping responses within which caring was integrated into their daily lives: balancing other activities with caring, immersing themselves into the caring role, and integrating the caring role thus giving them some purpose in life (Lewis and Meredith, 1988). Another study on 90 carers of adults with mostly physical disabilities and mental health problems describes a balancing/boundary setting mode of coping (Twigg and Atkin, 1994). Here, an element of separation between the carer and the situation becomes important. In this model carers firstly make sense of what is happening. For example, they quote the realisation that hurtful behaviour by the person being cared for was not meaningful in an interpersonal way, thereby enabling the carer to adjust to the situation. Secondly, setting limits in caring and not allowing themselves to be bullied by the person they were caring for enabled carers to cope. Thirdly, other carers in their study

adopted self-identity as a coping mechanism- i.e. these carers realised their value to society. From this perspective particularly, male carers viewed their role as more of an occupation. This view of caring relates to Kramer (1997), who proposes that caregiving tasks can be adapted to become part of a positive goal in life, thus enabling carers to cope better. In addition, this self-identity allows for contact with outside agencies and other carers, which in turn can constitute an important source of consciousness raising. This can have the effect of reinforcing carers' own sense of worth. Lastly, in this category, some carers were able to detach themselves emotionally as well as physically from the person they were caring for. For instance, they were emotionally and physically able to put space between themselves and the person they were caring for. As with the experience of stress, there are group differences in coping among carers. Twigg and Atkin (1994) found that more men than women were able to distance themselves from the situation and protect their sense of autonomy.

Caring for an older person changes in nature over time, it tends to be long-term and therefore carers' coping strategies need to adapt to the various situations they may experience in order to be effective, irrespective of their ethnic origin. More recently, Sistler (1989) and Wright *et al.* (1991) have commented upon the apparently limited effect of specific problem solving strategies. In the context of carers supporting older people in the community, many interventions appear to be focused on one aspect of problem solving: for example, training for specific dependency behaviours (McHaffie and Atkinson, 1992), which may be too limiting and too short in duration to be of real long-term use to carers. Tension and emotional distress which may arise from the caring role may have various causes and will therefore need to be addressed by different means, for instance carer support groups (Milne *et al.*, 1993). In relation to carers of older people having suffered a stroke and

carers of older people with a dementia, Matson (1994) found that tactical coping responses to specific hassles were negatively associated with stress and depression. He highlighted the coping strategy of :

*'...finding ways of meeting or balancing the needs of both carer and dependent person and showing empathy and respect for the individual, and sensitivity in interactions'.*

(Matson, 1994:342)

This approach is emphasising the more qualitative and personal aspects involved in supporting an older person in the community.

Following the discussion of the various internal mechanisms of coping, it is worth reiterating that perhaps no one coping strategy is effective in all situations. Much may depend upon the type of stressor encountered by individuals. Personality characteristics, subjective interpretation over an objective condition and a sense of control over a given situation further impinge on whether a carer is or is not able to cope. Importantly, structural constraints such as a lack of financial resources, or indeed the inability to access appropriate services, influence a carer's capacity to utilise suitable coping efforts. The next section of this chapter will now explore the external aspects of coping, namely that of social support, which is also regarded as a principal mediator of stressors (Pearlin *et al.*, 1990).

#### **4.5 Support to Carers**

Social support is viewed as the external coping mechanism; hence coping with the aid of social support is seen as a successful response to stress. Over the last few years many studies have therefore concentrated on the mediating role of social support between stress

and psychosocial adjustment, and whether it is an important factor in influencing an individual's physical and mental well-being (Pearlin and Schooler, 1978; Thoits, 1982, 1986; Wheaton, 1983; Lefcourt *et al.*, 1984; Cohen and Wills, 1985; Holahan and Moos, 1985; Norris and Murrell, 1990; Buunk and Hoorens, 1992; Matt and Dean, 1993; Neeleman and Power, 1993; Cohen *et al.*, 1994; Aymanns *et al.*, 1995; Cossette *et al.*, 1995). Although social support is generally assumed to influence well-being, it is possible that an individual's well-being and psychological distress may in itself influence social support (Matt and Dean, 1993). Here it is suggested that one symptom of depression is a person's removal of him/herself from friends and others, or indeed the withdrawal of others from that individual because of anti-social behaviour. Similarly, social support can have negative effects on an individual's well-being as it may increase stress levels and that stress itself can decrease the availability of support. In addition, people feel they give more support than they receive (Buunk and Hoorens, 1992). The exact role of social support in counteracting stress is thus unclear and contradictory. Nonetheless, research concerning carers has shown that there are three major factors that are important in helping carers to cope: i) time off from caring; ii) satisfaction with help from others in their informal network; and iii) receipt of services (Parker, 1992). Therefore, in the context of caring for older people, those who cope best with the emotional and physical strains of caring are those who not only have effective internal mechanisms, but also those who presumably have satisfactory formal and informal social support networks on which they feel they can draw when they wish to.

As with stress and internal coping processes, there is no one universal definition of social support, and many concepts are embraced by the term. One general description offered by Kaplan *et al.* (1977) is that support is the gratification of basic social needs, which can only

be met through social interaction with others. According to a review of the existing literature, an individual's basic needs can be met by five overlapping components (Fiore *et al.*, 1983), all of which relate to this study:

1. Emotional support:- the knowledge that one is cared for and loved (Cobb, 1976). As indicated in Chapter 2 (see section 2.4) 'reassurance of one's worth' can be considered an essential element of support in caring relationships. Equally important is the availability of counselling services to help carers cope with emotional problems (Richardson *et al.*, 1989; Sadler, 1990).
2. Cognitive guidance:- An aspect of social support which is regarded as the need for advice, guidance and information from formal and informal sources (Pitkeathley, 1991). This is particularly important for all carers, especially Asian carers who may have communication problems and who therefore may not fully understand the disabled person's condition. A lack of knowledge may make Asian carers feel insecure and undermine their confidence in providing adequate care (McCalman, 1990).
3. Socialising:- belonging to a network of communication (Cobb, 1976). This is especially important for carers who may be socially isolated, in particular Asian carers who experience a greater sense of isolation compounded by racism (Bould, 1990; Atkin and Rollings, 1993). In another study of carers it was found that other roles outside the family were associated with improved carer well-being (Stoller and Pugliesi, 1989). Williams *et al.* (1991), examining the effect of religious attendance and affiliation on psychological distress, found that religious attendance counteracts the adverse effects of stressful events.

Socialising is also important for the future: i.e. when the older person no longer requires care. McLaughlin and Ritchie (1994), in a study of 157 ex-carers, found that social networks had become fractured with many carers having lost the habit of socialising.

4. Tangible assistance:- this fourth component of social support concerns the provision of 'concrete assistance', such as helping with the shopping, gardening etc. It is also seen as having the knowledge that individuals within one's social network would provide tangible assistance (Braithwaite, 1990). Gilhooly (1984) reported that satisfaction with help from relatives was significantly correlated with carer morale. Thus, concrete help from others can be considered a crucial element in caring for older people who require physical support and/or supervision.

5. Availability of someone to confide in:- Previous research has shown that women (usually the main carer providing day to day support) who had someone to confide in were ten times less likely to suffer from an affective disorder such as depression (Brown and Harris, 1978). Research into carers in Northamptonshire reports how very much carers value the opportunity to share their feelings and anxieties with fellow carers (Mawby, 1993).

As can be seen by these different components, it is not just the amount of social support one has at one's disposal that matters, but also the source of support, for example, spouse, family, friends, religious involvement, professionals etc. Further, it is the type and quality of support- for example, whether emotional, confiding, behavioural, financial etc. that may be crucial elements in helping the carer to cope with the specific aspects of caring for an older person. As research has shown, social support can act in a compensatory role. It may also have a direct effect on an individual's well-being. However, in the context of this research, it

is the buffering hypothesis- i.e. the ameliorative effect of social support, which can be considered as most relevant. As outlined by Thoits (1982):

*'individuals with a strong social support system should be better able to cope with major life changes: those with little or no social support may be more vulnerable to life changes, particularly undesirable ones.'*

(Thoits, 1982:145)

Informal carers of older people may have to face undesirable life changes. For them to be able to cope better, the resource of a social support system may be seen as the mediating variable between stress and coping.

Another aspect of social support is its perceived efficacy, essential to an individual's coping strategies. Thoits (1986) argues:

*'Not just any significant other can supply effective coping assistance. I would argue that effective support is most likely to come from socially similar others who have faced or are facing the same stressors, and who have done so or are doing so more calmly than the distressed individual.'*

(Thoits, 1986:420)

For carers, empathetic understanding of their situation may be derived from both informal sources, for example friends and other relatives who are caring for an older person, and formal sources, for example carer associations, community nurses and General Practitioners. These professionals may be able to provide effective emotional and practical support. For Asian carers, who remain invisible to service providers and experience difficulties with access, support from formal sources is of particular importance.

Closely interlinked with the efficacy and availability of support is the very important distinction of perception of its quality and adequacy (Braithwaite, 1990). It is not only the number of social relationships available, but their perceived positive relevance to the individual's needs that is important. In other words, an individual may obtain actual beneficial support from only a very small number of significant others, rather than from a large social network which may not have any real effect on their psychological well-being: i.e. quality not quantity (e.g. Hirsch, 1980). Therefore, a carer would need to feel able to turn to only a few other people for help and support with bathing, shopping, etc..

Not only is social support important in ameliorating stressful stimuli, its value is also in a carer's perception of its importance. It is also true to say that a carer is unlikely to perceive social support which is not actually there or accessible- for example Asian carers of older people who are presumed to care for their own. Further, as previously outlined, many carers of older people assume the full responsibility of caring on their own with little or no help from either informal networks or service providers. Nonetheless, perceived access to social support from formal and informal sources may be regarded as crucial in enabling a carer of an older person to continue in their caring role.

#### **4.6 Conclusion**

The debates on community care for older people and other vulnerable members of society have resulted in a focus on informal carers. This interest has led to a need for a better insight into the experience and needs of carers. This chapter has therefore been mainly concerned with not only the understanding of the nature and pattern of informal care, but also the psychosocial impact of caregiving and its relationship to other factors such as coping and social support.

Studies on carers over recent years have highlighted the difficulties and disadvantages carers face. The evidence presented has shown that carers not only experience stress in caring tasks, they may also feel isolated and lonely, socially restricted and suffer the loss of employment opportunities. Many carers want to carry out their role with love, loyalty and generosity. Yet, carers are vulnerable members of society precisely because they care. The chapter has shown that caring for an older person does affect people's lives and influences individual experiences of caring. Given the importance of carers' capacity to care, the chapter has also explored how different carers may utilise social support systems and cope with their caring role. As such, this research has endeavoured to develop further our knowledge and understanding of the experience of caring for an older person.

Previous research has not systematically looked at the psychosocial impact of caring on carers from different cultural backgrounds. Although the circumstances of many carers from different cultural backgrounds are similar, this chapter has endeavoured to suggest some areas of differentiation in the experience of carers from the South Asian community (see Chapter Three for a detailed discussion on the importance of carers and ethnicity). The thesis now moves on to present the methodology used in this study on patterns of informal caring for older people.

## CHAPTER FIVE

### METHOD AND PROCESS OF THE RESEARCH PROJECT

#### 5.1 Introduction

This chapter describes the research methodology, together with its aims, objectives and hypotheses. It provides full details on the sample, the research design and its process. The chapter begins by furnishing a rationale for this study (section 5.2). It then outlines the research design (section 5.3) and supplies information about the sampling procedure and the selection of the carers of older people participating in this study (sections 5.4 and 5.5). Following this, the most appropriate tools to elicit both qualitative and quantitative data for this study are considered (section 5.6). A rationale for the interview schedules with any objective measures used is also detailed. The chapter then provides information on piloting, amendment of the interview schedules, training procedures for the interviews and details of how the study was carried out (sections 5.7 and 5.8). In the penultimate section some possible analyses are considered (section 5.9). The chapter concludes with some of the limitations of the research (section 5.10).

#### 5.2 Rationale for the Study

Community care policies have led to an increased focus on carers in general. Hence, a wealth of literature exists on carers' experiences of caring, but few research studies focus on carers from different cultural backgrounds. In recognition of this gap, this project will investigate the experiences of carers of older people from different cultural groups in Northamptonshire. This next section of the chapter describes the aims and objectives of the study from which the hypotheses relating to this research have been generated.

### **5.2.1 Aims and Objectives of the Project**

This research has two main aims. Firstly, the research examines differences in the carer groups' perceived morale, stress, coping levels and strategies used. Secondly, through analysing and comparing a range of factors, the study aims to explore differences in the situations and experiences of carers from three different communities.

In order to meet the above aims, the project has five main objectives:

- 1) To compare the social and demographic backgrounds of informal carers of older people from three different cultural backgrounds in the community.
- 2) To explore the motivations to care and the nature of care provided in the three different cultural groups of carers.
- 3) To identify and compare the experience of carers from minority ethnic and white indigenous groups in order to reach a better understanding of similarities and differences between different cultural groups.
- 4) To elicit data on perceived general morale, perceived stress and coping strategies in carers from three different communities.
- 5) To make suggestions to service providers for formal provision which may enable individual main carers to improve their situations, circumstances and experiences surrounding informal care in our community.

### 5.2.2 Hypotheses

As stated above, the overall aim of this study is to investigate the situations and experiences of carers of older people in three groups (Gujarati, Punjabi and white indigenous). In doing so, it particularly examines the psychosocial aspects of caring and its impact on carers from different cultural backgrounds. Hence, three hypotheses have been generated to explore carers' perceived morale, stress, coping ability and coping strategies.

1) Morale may be influenced by a need to adapt to change. Assuming the responsibility to care for an older person constitutes such a situation (see Chapter 4, section 4.2.1). Morale is also an outlook in individuals or in a group characterised by confidence, control and motivation (Wolman, 1974). Given that perceived morale must also be dependent upon how satisfied one is with one's life, it therefore encompasses such factors as self-esteem and self worth. In addition, given that members of minority ethnic populations are reported to be subject to barriers and disadvantages such as stereotyping, ethnocentric service orientation and myths surrounding informal care (Mehta, 1993), they may feel less satisfied with their life:

#### *Hypothesis 1*

*the level of perceived morale will significantly differ between informal carers in the Gujarati, Punjabi and white indigenous carer groups researched.*

2) Research on carers in general suggests that caring may result in increased levels of emotional strain or stress (see Chapter 4, section 4.2.2). The evidence available suggests that the task of caring is similar for minority ethnic caregivers (McCalman, 1990), as are the conflicts and stresses (Walker and Ahmad, 1994). However, the disadvantages

accompanying ethnicity seem to magnify their experience (Cameron *et al.*, 1989; Williams, 1990; Ahmad and Atkin, 1996). Therefore:

***Hypothesis 2***

*the level and experience of perceived stress will significantly differ between informal carers in the Gujarati, Punjabi and white indigenous carer groups researched.*

3) Coping refers to both internal and external dimensions (e.g. Holahan and Moos, 1987; Thoits, 1995 respectively). As indicated in Chapter 4 (section 4.5), factors that may help carers to cope include time off from caring, satisfaction with help from others and satisfactory provision of services, all of which are important in carer adaptation. Given that barriers to services from formal sources exist for minority ethnic communities (Blakemore, 1985):

***Hypothesis 3***

*there will be a significant difference between the three groups in terms of a) perceived coping ability, b) internal coping methods and c) external coping strategies.*

In addition to testing these three hypotheses, other factors and variables will be explored to add more meaning to the study. The following section describes the design for this study.

**5.3 Design of the Study**

The study adopts an independent subjects design, to compare the impact of informal caring on the three groups of carers of older people in Northamptonshire. The independent variable

is ethnicity (Gujarati, Punjabi and white indigenous carers). The dependent variables are the data generated by the semi-structured interview schedule on perceived morale, stress and coping ability, internal and external coping strategies.

#### 5.4 Population of Carers in Northamptonshire

In order to be able to select three cultural groups, the 1991 census was used to determine population numbers of minority ethnic groups in Northamptonshire (see Table 5.1).

**Table 5.1 The Ethnic Origin of People Aged over 60 Years as a Percentage of Total Populations in Northamptonshire**

Ethnic Group	Aged 60 years plus	Total
White	109160 (19%)	558491 (96.5%)
Black Caribbean	432 (10%)	4437 (0.8%)
Black African	18 (2.6%)	697 (0.1%)
Black Other	19 (0.9%)	1992 (0.3%)
Indian	412 (6.3%)	6580 (1.1%)
Pakistani	31 (4.3%)	725 (0.1%)
Bangladeshi	54 (3.8%)	1408 (0.2%)
Chinese	77 (5.8%)	1323 (0.2%)
Other Asian	63 (5.7%)	1104 (0.2%)
Others	76 (3.7%)	2050 (0.3%)
Base		578807 (99.8%)

Source: Wright (1993), data obtained from the 1991 census.

The data indicated that the two largest minority ethnic groups, both in terms of total numbers and in terms of those aged 60 years and above, were the black Caribbean

community (0.8%, 10% respectively) and the Indian community (1.1%, 6.3% respectively). These two groups were therefore initially identified as the best groups to target in terms of accessing possible carers of older people for comparison with carers of older people from the white indigenous population. As most carer research on the general population will have predominantly more indigenous whites, these were considered a good control group.

One element considered important for the study was that of languages spoken by the different minority ethnic groups. The inclusion of another group other than the white indigenous community who could be interviewed in English (for example the black Caribbean group), and which would thus reduce the need to employ interviewers, was initially a major consideration for this project given the limited financial resources. A pilot study with two white indigenous carers, two black Caribbean carers and two Indian carers was carried out.

One further factor deemed essential was the willingness and enthusiasm of carers of the various groups to take part. This would not only benefit the study itself, it would also be of value in identifying and accessing other carers known to carers taking part in the study. Following telephone calls and visits to local black Caribbean centres the feedback from this community, in terms of eagerness to participate in the research, was less positive than originally expected. Given the non-committal response, it simply was not possible to persevere with this group. This influenced the project to focus more on groups within the Indian community who initially expressed more of an interest in the research.

Early discussions with community groups in Northamptonshire revealed that the majority of the Indian population had migrated from the Gujarat and Punjab states as well as from East

Africa (originating from Gujarat). One main factor noted from previous literature and studies was that people from the Indian continent are generally described as Asian or South Asian (e.g. McCalman, 1990; Atkin and Rollings, 1993; Ahmad and Atkin, 1996; Anwar, 1998). These writers acknowledge that 'Asians' are not a homogeneous group, and the knowledge that one main difference between Gujaratis and Punjabis was that of language led the research to explore less obvious differences in these carer groups. Gujarati and Punjabi speaking carers were therefore chosen as the other major analytic groups for comparison with the white indigenous group of carers. It is important to recognise that language distinguishes these groups rather than religious following. Both Gujarati and Punjabi groups not only have a distinctive language and script, they also, as do white indigenous people, enjoy diverse religions and traditions with differing systems of practices, beliefs and relationships. Their traditional way of life may be reflected in the way they dress, their diet and the way they handle any given situation such as the caring role.

It is accepted that different migration patterns mean that the members of Gujarati and Punjabi groups will have settled in Britain at different times. As a result of these patterns, many members of the younger generations have been brought up here; it is therefore understandable that length of residence in Britain may also affect the extent to which people adapt to a western culture. Carers themselves may therefore have different attitudes in the way they view their caring role. As many of the older people requiring care may have different cultural backgrounds both to younger generations and between cultural groups, their expectations may also be different to those who are providing care. Older people represent original ethnic identity and thereby influence the family's later life. Owing to this, it will be possible to discern some distinct needs and problems of the different cultural groups of carers of older people.

Those participating in this study were limited to adult carers (aged 18 and above) residing in Northamptonshire. The definition of carers in this study accords with that used by the General Household Survey (1985: 1):

*'...people who were looking after, or providing some regular service for, a sick, handicapped or elderly person living in their own or another household'.*

Some of the carers looked after more than one older person and some older people had more than one informal carer. In general, it is difficult objectively to discern how these informal networks are functioning. Nonetheless, past literature has established that the locus of care is often with one main carer and it is on these carers that this study focused (e.g. Parker, G., 1990).

An important methodological consideration for this study was how to select the interviewees. The ideal would have been to have matched samples of possible participants for the study, reflecting the composition of the different carer populations, for example in terms of gender, age, relationship to the older person, disability of the cared-for etc. (e.g. Orme and Forbes, 1991). Due to the smaller population of people aged 60 and over (19% white and 6.3% Indian, see Table 5.1), the general isolation of carers, especially those from minority ethnic groups (McCalman, 1990), and taking time and resources into consideration, a matched sample was not a feasible option.

Formal service providers had expressed interest in the study and Northamptonshire Social Services at the outset of the project gave ethical clearance. Nonetheless, problems were encountered on two fronts. Firstly, despite visits and telephone calls to various GP surgeries,

social service departments and carer organisations, access to a comprehensive list of carers was denied for reasons of confidentiality. Secondly, it was often found that no such list existed. Consequently, in line with other studies on informal carers such as those by Nolan and Grant (1989) and Grant and Nolan (1993), the research was based on self-selection. In order for the project to proceed it adopted an opportunistic or convenience sampling method (e.g. Duffy, 1985; Given *et al.*, 1992; Fink, 1995).

## **5.5 The Sample**

The sample consisted of 50 Gujarati, 50 Punjabi and 50 white indigenous adult informal carers of older people domiciled in Northamptonshire. It included 121 women and 29 men.

### **5.5.1 The Sampling Procedure**

Carers see the caring process as a part of an ongoing relationship; in other words they see themselves as relatives or friends who help out, rather than as carers (Spackman, 1991). Within Asian communities, an even greater emphasis is placed upon these relationships with caring responsibilities being part of cultural norms (McCalman, 1990; personal communication from Dostiyo, 1993). Owing to the general invisibility of carers, especially in Asian communities, carers were recruited mainly through informal channels using personal networks, snowballing methods and contact with local white and Asian groups. This mode of sampling firstly enabled the identification of potential carers willing to participate in the research. Secondly, because of its more personal nature, it allowed for a minimum of refusals once contact had been made.

Nonetheless, because this was essentially a convenience sample, contact with carers from all three cultural groups was not as immediate as initially hoped. The recruitment of white

indigenous and Gujarati speaking carers was not as problematic as it was for the Punjabi group. After a period of six months, approximately 39 white indigenous and 30 Gujarati carers had been interviewed. However, the numbers for the Punjabi group was, at this stage, considerably less (15 carers). In order to bring the number of interviews from this latter group, in particular, up to the level of the other two carer groups, attempts were made to contact more Punjabi carers via the gurdwara<sup>2</sup>. Unfortunately, this approach was unsuccessful and there was considerable difficulty in gaining individual acceptance and access to carers from this community. What also emerged from contacting Asian community leaders was that, rather than becoming involved in research, many individuals found the need for some actual response to their problems. This feeling of being researched had also perhaps led to an initial distrust of the motives for the project.

Close and sustained liaison with different Asian groups such as Dostiyo and the Gharana Nivas Housing Association in Wellingborough (a housing association for mainly Gujarati speaking older people) gradually enabled more Gujarati and particularly Punjabi carers to be included in the project. Northam House in Kettering (a residential home mainly populated by white indigenous older people), which ran a weekly day group for Asians, and a Punjabi speaking Indian community worker in Kettering who was known to her community, also proved fruitful in finding more Punjabi carers for the interviews. In addition, sheer perseverance and active participation in a small voluntary group mainly for older Asians (the Shanti Group, Kettering) and many repeated visits to other community groups for older Asian people, slowly built up trust between the researcher and formal carers at the different centres. After some considerable time (6-18 months), staff eventually agreed to help by providing names and addresses of carers after consultation with them. Although trust and

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<sup>2</sup> Gurdwara 'the door of the Guru'. The Sikh place of worship (Singh and Smith, 1985).

endorsement of the project were gradually obtained, this had the effect of reducing the period for data collection. It was therefore necessary to stop searching for further carers who may have participated in the project. The final sample sizes of 50 white indigenous, 50 Gujarati speaking and 50 Punjabi speaking carers were considered adequate for making comparisons between the three groups.

### **5.6 Instruments**

Before embarking on the fieldwork, the nature of the interview schedule was discussed with a wide range of individuals and organisations such as community centres providing care to older people, community leaders, social services personnel, and carers known to the researcher. The aim here was both to incorporate their ideas and concerns into the interview schedule, and to gain confidence in the project.

The data for the research was collected by using a semi-structured interview schedule designed to collect a variety of information. Simple objective measures were also included to add weight to the study: Cantril's Ladder (1965) for perceived morale, and Rutter *et al's* (1970) Malaise Inventory for perceived carer stress (see Appendix 1, sections 7 and 8). Face to face in-depth interviews with the carers were conducted by the researcher in English and by trained bi-lingual interviewers proficient in both English and either Gujarati or Punjabi. This research design combines both quantitative and qualitative methods. This design was planned to maximise the inferential strength of the study and will be used to review and inform ways of supporting carers to maintain older people in the community. It will also provide the basis for interpreting the objective measures.

### **5.6.1. Rationale of the Interview Schedules**

Interviewing informal carers requires particular sensitivity, especially when it involves people who are caring for a loved one with a chronic or degenerative disease, or disability (Parker, 1993a). It also requires establishing an atmosphere of trust in which the interviewer is afforded an insight into actual life experience: i.e. 'seeing how it really is' by allowing participants to explain motivations for, and rewards derived from, their caring role.

To do justice to carers' valuable role in our society and to allow them to express individual concerns it was decided from the outset to conduct semi-structured interviews. It also became apparent early on in the pilot study that many Asian participants preferred to respond to questions in their mother tongue. It was therefore vital to the study to employ two sets of bilingual interviewers skilled in Gujarati and English and Punjabi and English to carry out many of the interviews. At the same time, the use of the semi-structured interview schedules would allow standardised data collection. The interview schedules consisted mainly of an informal and guided face to face interview with participants to derive a full picture of their caring life. Throughout the various sections of the semi-structured interview, open-ended questions were included in order to explore in-depth, individual concerns. These were designed to elicit qualitative information and to allow participants to give an accurate account of their lives and actions, thereby enabling a fuller flavour and variety of carers' knowledge to be gained. Together, the semi-structured interview and the objective measures administered were intended to afford a picture of the different experiences and situations of the different cultural groups.

### **5.6.2 Design of the Interview Schedules**

The semi-structured interview was mainly based on questions (see Appendix 1) designed to

describe caregiving dynamics and to look at individual relationships among caregiving structures, contexts and outcomes. In order to meet the aims and objectives of the study, the interview schedule included questions on structures such as the type of relationship between the older person and their carer, the carer's religious perspective and the carer's relationship with support services. Contexts such as the way the carer viewed his/her role in the caring process, and the way the carer viewed both the older cared-for person and significant others were also included. In addition, questions were asked concerning perceived stress and/or benefits derived from the caregiving role and individual coping strategies employed.

The semi-structured schedule was divided into eight sections. In order to develop a rapport between the interviewer and the participant, section one of the interview schedule began by asking questions that addressed the circumstances of the carer (e.g. Bhawuk and Triandis, 1996). This approach was intended to relax the participant and allow for open responses to more detailed questions regarding their caregiving role in the following sections (sections 2-4) of the interview schedule. The last four sections (sections 5-8) of the semi-structured questionnaire briefly concerned social and demographic data and the objective measures. The aims here were not to inhibit responses to personal and searching questions regarding carers' feelings about their role that may be considered potentially sensitive, nor to distract the interviewee from the very essence of the flow of the questions.

The first section of the interview schedule entitled 'the Nature of Care' opened the interview. Its aim was to determine the relationship of the carer with the cared for older person, how long that care had been provided, how the carer felt about his/her caring role, the type of support provided and any preparation the carer may have had for becoming a carer.

The aim of section two was to look at the physical and psychological aspects of caring as perceived by the carer. It identified their overall perceived health status and asked whether carers felt that their physical or emotional health had suffered as a result of caring. In addition, it enquired into feelings of stress using a five-point scale for its measurement. This section followed up the feelings involved in caring for an older person and/or benefits as well as any drawbacks derived from the caring role.

Section three asked about actual and perceived social support from formal and informal sources. Using a five-point scale, it determined levels of satisfaction with such supports and further questions were asked to elicit any problems encountered in the caregiving role. It also aimed to identify future needs and possible improvements as suggested by the participants. Finally, this section asked about the carers' spiritual and emotional perspectives on their lives.

Section four dealt with how the caring process affects the carer's everyday life. It identified individual feelings about the caring role and determined coping strategies and levels of perceived coping ability. The ten coping items listed in Q.69 (Appendix 1) regarding how carers may stay in control of stressful or difficult situations were adopted from determinants of coping suggested by Holahan and Moos (1987) and Barker *et al.* (1990). These consisted of both active and avoidance coping responses. One of the items classified as 'keeping busy' was somewhat ambivalent in that it could be rated as either active or avoidance coping behaviour (Barker *et al.*, 1990). Carers' comments during the interviews regarding this particular strategy indicated that the carers used it more as one of avoidance than active coping. Therefore, for the purpose of this research, the decision was taken to classify it as an avoidance coping mechanism.

Section five identified whether the carer had retired or was in paid employment. It delved into their employment status (according to Goldthorpe's classification outlined in Moore, 1987) and whether the caring role influenced not only the hours carers were able to work but also employment opportunities. The section then went on to find out about any voluntary work in which carers may have been involved. Finally, the section focused on financial details. It noted any state benefits received by both the carer and the older person receiving care, payments for services and determined any problems caring for an older person had on the carers' financial status.

Section six of the questionnaire sought information regarding older people and carers' social and demographic background (parts of which are asked in The General Household Survey, 1985) which would help not only to inform the research, but also enable some comparison. It therefore dwelt on the older person's impairment/disability, residence, age range of both the older person and their carer, ethnicity, religion, housing and time spent caring. Given that details concerning household income may have been a sensitive issue to some carers, this question was placed towards the end of the questionnaire (e.g. Bell, 1993).

The next part in this section of the chapter will now outline the objective measures (sections 7 and 8) used in this research as part of the interview schedule.

### **5.6.3 The Objective Measures**

As the semi-structured questionnaire mainly asked how carers perceived their feelings and experiences, it was considered important to include some simple objective measures for comparative purposes. In addition, it was intended that the inclusion of these measures would enable participants to focus their feelings quite specifically regarding their caring

role. Although no rating scales have been specifically developed for cross-cultural application on informal carers in Britain to assess stress, social support, coping strategies and general morale (personal correspondence from Professor Ebrahim, 1994), the inclusion of simple objective measures is deemed a complementary and valuable source with which to increase the inferential power of the study. Given possible limitations, the objective measures can be used in comparison with other studies on carers. Nonetheless, at this point it is also important to point out that caution will need to be exercised when drawing conclusions from findings generated from objective measures used, which are not culturally sensitive. The following two sections (5.6.4 and 5.6.5) describe the two measures chosen for quick and easy administration in this study.

#### **5.6.4 The Effect of Caring on Carers' Perceived General Morale**

An assessment of feelings of general morale was obtained by using Cantril's Ladder (1965). To measure morale the participants were asked to imagine that, if the top of the ladder represented the best possible life and the bottom represented the worst, where would they place themselves on the ladder. Scores were given from 10 to 1 from the top to the bottom of the ladder. This scale measured participants' feelings regarding their caring role at that time (not specifically addressed in the questionnaire) and can be said to represent carers' perceived general morale. Previously used in caregiver studies (Stoller and Pugliesi, 1989; Bose, 1991), Cantril's Ladder had the advantage of being easy and quick to administer, it was not considered ambiguous and was therefore easily understood. In addition it was non-threatening and, because of its simplicity, it was considered applicable to a cross-cultural population. Furthermore, Palmore and Luikart (1972) reflect on its use as a self-anchoring measure, in the sense that it pertains to an individual's sense of maximum and minimum life satisfaction, and its reliability as a continuous and theoretically equal-interval measure.

### 5.6.5 The Effect of Caring on Carers' Perceived Stress

Rating scales to measure psychological well-being in carers have included the General Health Questionnaire (GHQ) developed by Goldberg (1978). Although this measure has been used in British research to rate carer stress in previous carer studies (e.g. Gilleard *et al.*, 1984; Levin *et al.*, 1989; and Russell *et al.*, 1989), its format was deemed inappropriate for use in this project. The main reasons for its non-inclusion were that it can be fairly lengthy (e.g. the GHQ-30 that has thirty questions with quite complicated responses) and it included unsuitable questions on suicidal thoughts.

Another measure of stress is the Malaise Inventory (Rutter *et al.*, 1970, see Appendix 1, section 8), which has been used in studies on those who care for children with dependency needs (e.g. Quine and Pahl, 1985; Bose, 1991; Cairns, 1992) and carers of adults in need of care (Wright, 1986; Quine and Charnley, 1987; Nolan and Grant, 1989; Spackman, 1989). This was developed from the Cornell Medical Index to assess psychosomatic symptoms. Respondents are asked to respond 'yes' or 'no' to simple statements related to physical, emotional and psychosomatic criteria. Each 'yes' receives a score of 1 and each 'no' is scored 0. In line with previous research, a score of 5 or above is taken as being indicative of stress (Nolan and Grant, 1989; Bose, 1991). This measure was considered a valuable addition to the study, as it was quick and simple to employ. It also assessed medical symptoms not addressed in the semi-structured questionnaire. There has been some dispute about the trustworthiness of the scale for testing empirical hypotheses about degrees of stress. Grant *et al.* (1990) reappraised the Malaise Inventory on 527 members of the Association of Carers. They suggested that, although the Malaise Inventory may consist of two or more separate dimensions (psychological malaise and physical malaise), it nevertheless generates fully acceptable internal consistency, content validity and construct validity.

The limited literature available suggested that the experience of physical and emotional aspects of care giving for South Asian carers is similar to that of white carers (McCalman, 1990; Ahmad and Atkin, 1996). Although previous studies using the Malaise Inventory (Rutter *et al.*, 1970) do not provide details on the ethnicity of participants, its simplicity and the fact it assesses both physical and emotional factors, meant that it was considered appropriate to this research on Asian carer groups.

### **5.7 Piloting of the Interview Schedules**

Following discussions with the different communities it was recognised that Asian people, and in particular older Asians, may have felt more comfortable to be interviewed in their mother tongue rather than in English. As the researcher (white indigenous) would have been unable to conduct interviews in either Gujarati or Punjabi, the interview schedules were changed from an initial qualitative approach to a more quantitative one with the aid of a more semi-structured interview schedule. This allowed the data collection to be standardised with the use of trained interviewers skilled in the appropriate language. In addition, the previous literature (see McCalman, 1990), visits to community groups and the piloting of the interview schedules, led to the recognition that Asians may age earlier than the rest of the population. Therefore, the study decided not to adhere to 65 years of age as a definition of an older person. A starting point of 55 years of age was thus chosen.

Some of the participants were unwilling or unable to comment on the aspect of household income. As enquiry into financial circumstances may constitute a very sensitive issue to many people, interviewers were instructed not to pursue this question if the participant seemed hesitant.

### **5.7.1 Further Piloting of Interview Schedules**

Following the amendment of the semi-structured interview schedule, it was then repiloted on 5 Gujarati speaking, 3 Punjabi speaking and 10 white indigenous participants by the researcher and two trained interviewers. The feedback on both the semi-structured interviews and objective measures was positive, in that the interviews ran smoothly and no other changes were necessary. In particular, the objective measures were found to be quickly and easily administered and the ratings contained within readily understood by the carers. The training of the two interviewers recruited to carry out the main piloting of the interview schedules took place prior to this procedure. Nonetheless, since the training of interviewers skilled in Gujarati and Punjabi was an ongoing process, this next section describes their training in more detail.

### **5.7.2 Training of Interviewers**

Cultural matching of interviewers with participants, for example on ethnicity, race, social class, gender, age, language and values, has been identified as an important aspect of culturally competent research. However, ideal matching on all these attributes is rarely possible (Sawyer *et al.*, 1995). Language can be viewed as a reflection of culture where deeper and more subtle communication can take place. Many of the minority ethnic participants in this research had English as a second language. Where this was the case and participants preferred to use their mother tongue, bilingual interviewers of the same culture and skilled in their particular language were employed to carry out the interview. Three of the nine interviewers (two Punjabi, one Gujarati) had acted as bi-lingual interviewers in other studies for University College Northampton. The remainder were recruited through local community groups in Northampton, Kettering and Wellingborough.

The employment of interviewers skilled in the appropriate language enabled the interviewer not only to gain informed consent for the interview; it also permitted the use of terminology with which the participant was familiar. Importantly, it furthermore allowed for the clear understanding of any questions asked and made mutual understanding between interviewer and participant possible (Marshall and While, 1994). In addition, the issue of attributing different meanings in the use of different languages could be addressed (Clarke, 1992), allowing less scope for misinterpretation of questions and answers. The inclusion of probes in the semi-structured interview schedule further assisted the interviewer in reaching clear responses. Words such as 'stress' could be exchanged for a more culturally appropriate terminology. Communicating with individuals who think and speak in the context of the same language and culture enhances the validity and reliability of the information elicited (Headley, 1992). However, it can also be argued that sensitivity and collaboration are equally fundamental to the development of culturally competent research and therefore the researcher herself conducted a number of interviews with Gujarati and Punjabi speaking participants for whom speaking English did not present a problem.

The basic aims of the study were explained in detail to all nine interviewers (all women aged 23-45 years). Relevant statistics and other information were highlighted and interviewers were provided with a written outline of the research (see Appendix 2). Training sessions were initially held for two Gujarati speaking and two Punjabi speaking interviewers. As time elapsed, however, further training sessions were held for different interviewers (a total of 4 Gujarati speaking and 5 Punjabi speaking). Basic guidelines to interviewing techniques were used in the training sessions: for example the requirements which needed to be met, how to maximise participants' responses and how to follow the interview schedules correctly (see Appendix 3). Particular attention was paid to open-ended

questions intended to generate in-depth responses to complex and sensitive issues and allow further probing for information. This method also ensured that all questions and answers were clearly understood by both parties.

Before the actual fieldwork, interviewers were asked to practise using the interview schedule on one another in order to familiarise themselves with it and become more fluent with its process. This served a dual purpose, in that they could become proficient at translating the material into the appropriate language and then translating it into English writing on to the interview schedules. The researcher held further meetings with the interviewers to ensure their confidence with the interview schedules. Interviewers were also advised that the length of the interview process might vary between 1 and 2 hours.

Given that some carers felt isolated and often had no one to talk to and might therefore frequently 'wander off' the subject, interviewers were informed how to avoid this situation, such as by suggesting that they have a more informal chat after the interview. Due to the nature and length of the interviews and the travelling involved, interviewers were paid for their work from the research budget.

### **5.8 Procedures**

Before the actual fieldwork, names and addresses of carers were forwarded to the appropriate interviewer. Initial contact was then made either by telephone or in writing. Although similarly approached, most of the white indigenous sample (90%) were obtained through a personal network and 'snowballing'. Gujarati speaking and Punjabi speaking interviewers also found that once the fieldwork had commenced more names were recommended to them by the same means.

Interviewers were asked to arrange mutually convenient appointments with the participants, for example by giving a choice of times and days of the week. The purpose of the study was explained and, once informed consent had been obtained from the carer, all interviewers were instructed on how to ensure complete privacy for the interviews: for example, by arranging for the interview to be conducted either whilst the older person was elsewhere, or whilst the older person being cared for would not be present in the same room. This would ensure a more open discourse. Sometimes this necessitated initial informal visits to families to build up trust and explain the study in more detail to participants. On two occasions, the researcher herself conducted the interviews elsewhere away from the carer's home. However, where some form of privacy was not possible the interviews either did not take place or were discounted.

Further to this issue of privacy, all interviewers were trained to ensure complete confidentiality throughout the interview and thoroughly debrief participants immediately after. All interviewers were also instructed to offer printed information in their particular language on benefits and carer support groups to carers. These were obtained by the researcher prior to commencement of the interviews in order show a willingness to return thanks for their time and trust given to the project.

Given the nature of the study, two of the interviewers themselves felt they needed debriefing. They had found some of the participants' experiences and situations particularly upsetting. Therefore, the social worker or link worker connected to the appropriate community group made herself available to deal with any problems encountered.

The community groups involved in the project also assisted by overseeing the project and how it was conducted to maintain ethical standards throughout. Different community groups would pass names and addresses of carers on to one another, which assisted in the recruitment of carers who were aware of the research. Quality control checks were carried out by revisiting the community groups participating in the research. By chatting to group leaders and older people and their carers, it was possible to check that the interviews had taken place satisfactorily. In addition, the researcher sometimes accompanied the interviewer when interviews were taking place. Interview schedules returned by individual interviewers were thoroughly checked by the researcher and any problems with the interview schedules addressed by discussion with them.

### **5.9 Possible Analyses**

This section on the method and process of this research project outlines how the information collected was analysed. It begins by assessing the quantitative data generated by the study. Following this, the chapter describes how the qualitative material derived from the open questions included in the semi-structured interview was analysed.

Quantitative data collected was coded and entered on to SPSS 6.0. (Statistical Package for Social Sciences, Norusis, 1993). Frequency checks were carried out to ensure the data had been correctly entered. Various statistical methods were then employed to analyse the data. Firstly, box plots and histograms needed to be generated on the data concerning the three cultural groups for both the objective measures employed (Cantril's Ladder and the Malaise Inventory). Secondly, as the data showed itself to be of a non-normal distribution, a comparison of medians on the data was used. Following this, an appropriate non-parametric one-way analysis of variance was used to determine whether there was any significant

difference between the three cultural groups. Where findings showed that a significant difference between the three cultural groups of carers did exist, an appropriate post hoc test was used to find with which cultural group the difference lay.

Much of the other quantitative information contained in the interview schedule consisted of categorical data and five point rating scales, for which the use of non-parametric tests were more appropriate. Therefore, tests such as chi-square tests of association and Spearman's rho were employed to establish the relationship between the three cultural groups and different aspects of caring.

In order to establish links between the quantitative data and the qualitative information a thematic approach was taken (e.g. Ely *et al.*, 1993). Material collected from the open questions contained within the semi-structured questionnaire were categorised according to the three hypotheses concerning morale, stress and coping. Qualitative information elicited will have been guided by the interview schedule.

In order to categorise the material, it was firstly grouped according to the carer's ethnicity. The information provided by each participant was noted, as were specific concerns relating to themselves and their cultural group. It is hoped that this method of analysis for the qualitative material will afford a clearer understanding of the personal experiences of carers from different cultural groups, and will enable some specific similarities and differences between the groups to be discerned and discussed. Quotes from the carers were recorded *ad verbatim* or as noted by the bi-lingual interviewers, so as not to lose the essence of the conversation.

### **5.10 Limitations of the Study**

This chapter has outlined the method by which the research was carried out. In view of the boundaries of time and resources available, the limitations concerning the way the project took shape are now outlined.

The remit of this project was to look at the experiences of informal carers in three cultural groups. This was achieved with the use of two different Asian groups of carers (Gujarati speaking and Punjabi speaking), who were selected for comparison with white indigenous carers. In line with other studies on carers, a self-selecting and opportunistic sampling method was employed. However, had there been more time and resources, a matched sampling approach might have elicited more directly comparable data between the three cultural groups researched. An additional point that needs to be made concerning the selection process of carers is that, given the non-committal response from the Black Caribbean population at the outset of this project, there was not sufficient time to persevere with this group. It is hoped that future research may be able to include carers originating from the latter group.

The number of fifty carers in each cultural group was sufficient for comparisons to be made. Statistical analyses were possible, however a larger sample size and/or matched samples would be required to develop a more sophisticated level of enquiry. Hence, more large-scale research and/or more proportional allocation in terms age, gender, nature of disability/limitation in the older person may be required for a better understanding of the issues.

Tape recording the interviews with the Gujarati and Punjabi speaking carers would have been the ideal for the wealth of qualitative material it would have produced. However, the translation costs were not viable for this research. Future small-scale studies may consider this approach, and given sufficient resources have them translated into English. This option would also allow more in-depth analyses of pertinent issues in the experience of caring for an older person.

All the interviewers were female, as was the researcher. This factor may have had a bearing on the low numbers of male carers participating in the project (29 men as opposed to 121 women), given that the proportion of male carers across Britain is much higher (see Parker G., 1990; GHS, 1990). The inclusion of male researchers to attract more male carers in future research is an important consideration.

One final consideration arising from this study, which is important for future research on the psychosocial aspects on caring in a multi-cultural society, is the fact that no objective measures for cross-cultural application could be found. Nevertheless, with regard to the present project, it has been established that the physical and emotional aspects of caring are similar for carers, irrespective of ethnic origin. Therefore, measures used in other carer research were included in the project. However, as indicated, caution will need to be exercised when drawing conclusions from the use of objective measures that are not especially designed for employment on different cultural groups. It is hoped that in the future, culturally specific rating scales will be developed for use in carer research both nationally and internationally.

### **5.11 Conclusion**

This chapter has presented the rationale for the method and process of the research used on carers of older people from three different cultural groups. Its aims, objectives and the hypotheses generated have been described.

Throughout the chapter, the different ways in which information was collected have been presented. Due to the sensitive nature of the study, and to allow carers to relate their experiences, face to face interviewing was adopted. This method also meant that qualitative as well as quantitative material could be collected. This combined information can only aid our understanding of caring in the community.

Although there were limitations with the study, information amassed regarding the nature of caring for an older person in the community has allowed more of an insight into the experiences and psychosocial aspects of caring in different cultural populations. It is hoped that this small-scale study on the carers from the three different groups will help to inform future research.

The ensuing chapters will now present the information gathered throughout this research. They begin by describing in detail the social and demographic characteristics of the carers taking part in this study (Chapter 6). The following chapter furnishes the quantitative analyses and qualitative material relating to the first two hypotheses regarding perceived morale and stress. The final results chapter (Chapter 8) takes a similar format and concentrates on hypothesis 3 relating to the carers' coping levels and strategies employed.

## CHAPTER SIX

### THE CARERS AND THOSE THEY CARE FOR

#### 6.1 Introduction

To introduce the one hundred and fifty informal carers participating in this study, this chapter presents a detailed examination of their social and demographic characteristics. The sample consisted of adult main carers of older people from three different cultural groups (fifty Gujarati, fifty Punjabi and fifty white indigenous). The social and demographic backgrounds of the informal carers and those they care for will be compared both between cultural groups and with other relevant research. The chapter is divided into three parts.

The first section (section 6.2) focuses on the characteristics of the informal carers. It begins by assessing the distribution of carers in the study across Northamptonshire. This is followed by a comparison of age, gender and socio-economic status. It then concentrates on language and communication factors that pertain mainly to the Gujarati and Punjabi carers in this study. The section ends by taking a closer look at the major religious affiliations of the three groups.

Section 6.3 centres on social and demographic data on the older people in receipt of care. Initially the nature and distribution of age and gender are presented. This is followed by a description of their disability. The section concludes by concentrating on the socio-economic position of older people and state benefits received.

The final section (section 6.4) focuses on both the carer and the older person. It firstly examines the relationship of the carer to the cared-for older person. It then takes a more detailed look at where care is received and types of help given. Finally, this section

investigates the number of hours devoted to caring and how long the carers in this sample have been caring for the older person.

The purpose of presenting these data are, firstly, to explore similarities and differences between the three different cultural groups: for example, who is doing the caring, whom they are caring for and the caring relationship. Secondly, this sample of carers will be compared to other studies of informal carers of older people. The first main part of this chapter now begins with the location of the carers.

## 6.2 The Distribution of the Carers in Northamptonshire

The geographical distribution of the three cultural groups can be examined in the context of the two Community Health Councils in Northamptonshire (North and South). Northants-North consists of Kettering, Corby, Wellingborough, Rushden, Oundle and surrounding areas. Northants-South includes Northampton, Towcester, Brackley, Daventry and surrounding areas.

**Table 6.1 The Distribution of Carers by Community Health Council**

District	Gujarati	Punjabi	White	Total
Northants-North	25 (50%)	33 (66%)	43 (86%)	101 (67%)
Northants-South	25 (50%)	17 (34%)	7 (14%)	49 (33%)
Base	50 (100%)	50 (100%)	50 (100%)	150 (100%)

Table 6.1 shows that amongst the one hundred and fifty carers, two thirds (n=101, 67%) lived in the Northants-North area. Obviously, this means that unequal numbers of carers were sampled from the two different administrative parts of the county.

The majority of carers from the white indigenous group (n=43, 86%) lived in the Northants-North area. This over-representation is explained by the fact that over two thirds of these respondents (n=36, 72%) were mainly recruited through initial contact with the researcher's personal network of known carers, and the remainder (n=14, 28%) were contacted using snowballing methods whereby carers interviewed would recommend other carers. A large number of the Gujarati (n=22, 44%) and Punjabi samples (n=32, 64%) were obtained through informally organised community groups across the county accounting for a more even distribution in the community health council division. Unfortunately no information exists on exact census numbers of populations for specific cultural groups, such as Gujarati and Punjabi speaking people, either in the county or nationally, making accurate comparison between this study and other data impossible. This important factor highlights the fact that ethnic monitoring systems currently employed do not allow for more detailed analysis.

### **6.2.1 Carer Age and Gender**

The age group most likely to care for an older person is 45-59 years (especially married women) as this is when many individuals are most likely to have ageing parents whose health may be beginning to deteriorate (Parker, G., 1990; GHS, 1990). The data in Table 6.2 accord with this as they show that the largest group providing care to older people in this research were carers aged 41-55 years (n=59, 39%), of which the majority were women (n=51, 86%). The figures also revealed that over three quarters of carers in this age group (n=48, 81%) were indeed caring for a parent or parent-in-law. Interestingly, the data also shows that almost as many carers as those aged 41-55 years were aged 26-40 years (n=52, 35%). Again, most of these were women (n=44, 85%) and most were also caring for a parent or parent-in-law (n=39, 89%). The majority of women in this group of carers were from the Gujarati and Punjabi carer groups (n=17, 39%; n=19, 43% respectively).

**Table 6.2 Carer Age and Gender by Ethnicity<sup>3</sup>**

Carer's Age	Gujarati		Punjabi		White		Total
	M	F	M	F	M	F	
18-25 yrs	0	0	1 (2%)	1 (2%)	0	0	2 (1%)
26-40 yrs	7 (14%)	18 (36%)	1 (2%)	20 (40%)	0	6 (12%)	52 (35%)
41-55 yrs	2 (4%)	15 (30%)	6 (12%)	13 (26%)	0	23 (46%)	59 (39%)
56-70 yrs	1 (2%)	6 (12%)	3 (6%)	5 (10%)	5 (10%)	9 (18%)	29 (19%)
71+ yrs	0	1 (2%)	0	0	3 (6%)	4 (8%)	8 (5%)
Base	50 (100%)		50 (100%)		50 (100%)		150 (100%)

Table 6.2 exhibits data for the total numbers of carers from the three different cultural groups. It shows there were more Gujaratis and Punjabis in the younger age groups of 18-40 years ( $n=25$ , 46%;  $n=23$ , 43% respectively) in comparison to the number of white indigenous carers ( $n=6$ , 11%). This latter group formed the largest majority in carers aged 56 years and over ( $n=21$ , 57%), whereas there were fewer carers from both the Gujarati and Punjab carer groups in this older age band ( $n=8$ , 22%;  $n=8$ , 22% respectively). Given this difference in age groups a chi-square test was carried out on age and ethnicity. A highly significant association between age and ethnicity was revealed (chi-square=18.92,  $df=2$ ,  $p=0.000$ ). From an examination of the data in Table 6.2 it is clear that the difference lies with the fact that the vast majority of white indigenous carers were situated in the older age group of 41 years and over ( $n=44$ , 88%). Conversely, only one half of Gujarati and Punjabi carers were aged 41 years and over ( $n=25$ , 50%;  $n=27$ , 54% respectively).

Further examination of the figures also revealed that over three quarters of the Gujarati and Punjabi carers ( $n=19$ , 76%;  $n=16$ , 76% respectively) in the younger age group of 26-40 years, and most Gujarati ( $n=10$ , 59%) and almost one half of Punjabi carers ( $n=9$ , 47%)

<sup>3</sup> In this and all following tables M denotes male and F denotes female.

aged 41-55 years were caring for a parent or parent-in-law aged 55-75 years. However, only a total of five white indigenous carers from these two age groups were caring for a parent or parent-in-law aged 55-75 years. This finding accords with previous work which finds that, on average, minority ethnic groups are younger than the white indigenous population (Growing Older, 1981, Cmnd. 8173; Atkin, 1992; Atkin and Rollings, 1993), hence carers from Asian communities are also likely to be younger than the indigenous population.

Table 6.2 also shows the numbers and percentages of male and female carers from the three cultural groups participating in this study. Surveys have shown that caring is mostly carried out by women. For example, the GHS (1990) reported that 17% of women in their sample of the general population were carers in comparison to 13% of men who were caring. As shown in Table 6.2 above, although there are similar numbers of men and women across the three cultural groups of carers, there is a marked distinction in the proportions of male and female carers in this study (n=29, 19%; n=121, 81% respectively). This striking difference may be explained by the relatively smaller sample size than the GHS and the way in which the participants were sampled: i.e. through the female researcher's personal network, snowballing and local community groups largely run by women. In addition, the fact that all the bilingual interviewers employed for this research were women may mean that, in this study, female carers were oversampled (see Fenton *et al.*, 1995). Given this discrepancy in total numbers between male and female carers, caution should be exercised when drawing conclusions from the whole sample.

### **6.2.2 The Socio-economic Status of Carers**

Caring for an older person requires time. This has implications for carers' employment and earnings (Richardson *et al.*, 1989), and it can also have an impact on the number of hours a carer can work. In addition, a carer's income may not only affect their own family's quality of life, but it may also influence the quality of care they provide.

Information regarding carers' paid employment, occupational class and state benefits received was obtained through the interview schedule (see Qs 75-79, Q83, Appendix 1). Table 6.3 shows that, out of the whole sample, only a small number of carers (n=11, 7%) were retired, almost one half were not seeking employment (n=69, 46%) and only two carers (both Punjabi males) were seeking employment.

**Table 6.3 Employment Status of Carers by Gender and Ethnicity**

Employment Status	Gujarati		Punjabi		White		Total
	M	F	M	F	M	F	
Retired	0	2 (4%)	0	1 (2%)	3 (6%)	5 (10%)	11 (7%)
Not seeking Employment	5 (10%)	21 (42%)	3 (6%)	26 (52%)	3 (6%)	11 (22%)	69 (46%)
Seeking Employment	0	0	2 (4%)	0	0	0	2 (1%)
Full-time	5 (10%)	12 (24%)	4 (8%)	5 (10%)	2 (4%)	9 (18%)	37 (25%)
Part-time	0	5 (10%)	2 (4%)	7 (14%)	0	17 (34%)	31 (21%)
Base	50	(100%)	50	(100%)	50	(100%)	150 (100%)

The data in Table 6.3 show that, of the carers eligible to work almost one half were not in paid employment (n=71, 47%). Table 6.3 also shows that, of this number, male carers were as likely as the female carers not to be in paid work (n=13, 50%; n=58, 51%). This finding accords with other research on informal carers where similar proportions of male and female carers were not in employment (Glendinning, 1992). It can be argued that lower rates of carers' participation in the labour market may not be due to caring responsibilities, as people who are not in paid employment are more likely to take on a caring role than those who are already in paid work (Glendinning, 1992). On the other hand, eleven carers in the present study had given up work in order to care for an older person. Unfortunately, the number and percentage of carers who had given up paid employment in order to care cannot be

compared to the GHS (1985, 1990), which did not collect this information. Nonetheless, Phillips (1993) reported that 37% of carers felt that, because of their caring responsibilities, they might have to give up work or retire early. These figures were compiled for all forms and ethnic status of carers combined and are therefore not directly comparable. However, taken together with the information from the present research and other studies, which echo the findings of the above survey (e.g., Lewis and Meredith, 1988; Twigg and Atkin, 1994), it seems that the employment prospects of carers are certainly adversely affected as a result of the demands of caregiving. In addition, further examination of the data showed that the great majority of carers who had not retired and who were not in paid work were caring for more than twenty hours per week (n=60, 84%). Of these over one half (n=33, 55%) were caring for more than 100 hours per week. Clearly, a heavy involvement with caregiving precludes many carers from even trying to participate in the labour market.

Carers in paid employment (n=68, 45%) were asked whether they worked full-time or part-time. Of the whole sample of 29 men and 121 women caring for those aged fifty-five years and above, almost one half of the men and women (n=13, 45%; n=55, 45% respectively) were in paid employment and caring for an older person. Table 6.3 shows that of the thirteen men employed, eleven were in full-time employment (85%) and only two were in part-time paid work (15%). In contrast to this, only twenty-six (47%) of women in paid employment were in full-time paid work, and twenty-nine (53%) were in part-time employment. This apparent gender difference may be due to women taking on other responsibilities, such as childcare and other household duties, and reflects what might be found in wider society. Accordingly, female carers are more likely than male carers to take on part-time employment. Not surprisingly, other research has also found that female carers, rather than male carers, were in part-time or casual paid work (Glendinning, 1992).

The data on carers' employment status, displayed in Table 6.3, also demonstrate some differences between the three cultural groups. The highest number of both male and female carers in employment were from the white indigenous sample (n=28, 41%), compared to twenty-two (32%) of the Gujarati carers and eighteen (26%) of the Punjabi carers. Factors which may account for the lower number of carers in paid employment in these two minority groups include education and language barriers, in particular for Asian women who may have had little opportunity to learn English (see Chapter 3, sections 3.3.1, 3.5.1).

For women there are more specific cultural issues, such as the tradition that women do not work outside the home and mix with men (Anwar, 1998). In addition, both the Gujarati and Punjabi groups were younger than the white indigenous carers (see Table 6.2) and three times more women in both Gujarati and Punjabi carer groups had younger children (n=18, 45%; n=18, 46% respectively) in comparison to female white indigenous carers (n=6, 14%). These distinctions may have affected the opportunity of the Gujarati and Punjabi groups to participate in paid employment as much as the white group. One further element that may be present is that of racism which, as indicated in Chapter 3 (see section 3.3.1), perpetuates racial inequality and discrimination.

Information regarding carers' employment status was classified according to Goldthorpe's classification (outlined in Moore, 1987). Carers were asked about the nature and type of paid employment they undertook (see Q. 76, Appendix 1). This generated information about the occupational class of female carers across the three cultural groups (see Table 6.4).

**Table 6.4 Female Carers' Occupational Class<sup>4</sup>**

Occupational class	Gujarati	Punjabi	White	Total
Professional	0	0	1 (4%)	1 (2%)
Managerial	1 (6%)	1 (8%)	2 (8%)	4 (7%)
Clerical	3 (18%)	1 (8%)	5 (19%)	9 (16%)
Self-employed	2 (12%)	1 (8%)	3 (11%)	6 (11%)
Technical	3 (18%)	1 (8%)	5 (19%)	9 (16%)
Skilled manual	3 (18%)	3 (25%)	8 (31%)	14 (25%)
Semi/unskilled manual	5 (29%)	5 (42%)	2 (8%)	12 (22%)
Base	17 (101%)	12 (99%)	26 (100%)	55 (99%)

At first glance, the occupational status profiles of each particular cultural group appear rather similar. However, upon closer inspection some differences emerge between the percentages of females employed from the different cultural groups. Table 6.4 shows that almost 1 in 5 Gujarati and indigenous white females were in clerical and technical employment (18% and 19% respectively), but only 8% of the Punjabi female carers were included in each of these categories.

Interestingly, more indigenous white female carers were in skilled manual occupations than either Gujarati or Punjabi women (31% as opposed to 18% and 25% respectively). The largest difference between the three groups is present in the semi/unskilled manual occupational category. Here, considerably more Asian female carers (Punjabi women in particular) were employed in semi/unskilled work than white indigenous female carers

<sup>4</sup> For this categorisation the numbers of employed males were considered too small for reliable examination.

(almost one half of Punjabi females  $n=5$ ; almost one third of Gujarati females  $n=5$ , as opposed to less than one tenth of white indigenous females  $n=2$ ).

When looking for overall differences between the three cultural groups, the most apparent factor is that two thirds ( $n=8$ ) of Punjabi females were employed in lower status occupations (skilled and semi/unskilled manual) compared to almost one half of Gujarati females ( $n=8$ ) and over one third of white indigenous female carers ( $n=10$ ). Again, language ability and reading and writing skills may be an important factor in accounting for the lower occupational status of Asian females.

Detailed exploration of the data collected showed that carers in paid employment were affected in several ways by their caring role. Over one third of all carers ( $n=27$ , 40%) found that caring for an older person had affected the numbers of hours they were able to work. For male carers ( $n=9$ ) it was more a matter of not being able to work late. Some of the female carers expressed a wish to work full-time ( $n=5$ , 18%), but were unable to because of caring and other commitments. This factor may therefore contribute to the high number of female carers in part-time employment. These findings accord with other research that has found restrictions experienced by employed carers because of their caring commitments (Lewis and Meredith, 1988; Richardson *et al.*, 1989; Glendinning, 1992; Twigg and Atkin, 1994).

A total of nineteen carers (28%) consisting of three men and sixteen women reported that caring encroached on their holiday entitlements; sixteen carers (four male, twelve females) related that course attendance at work was affected. Nine of the carers reporting a curtailment of course attendance opportunity also thought that this influenced promotion prospects. Eight carers actually reported that the caring commitment was a determining factor in the type of work they were able to do. Again, these findings accord with other

research on carers who similarly found loss of employment opportunities in carer research (e.g. Glendinning, 1992 and see Chapter 4, section 4.2.2).

It has been shown that the majority of the carers in this study who were eligible to work (n=71, 51%) were not in paid employment. Of these, eleven carers had to give up work in order to care for the older person and two were actively seeking employment. Hence, it can be argued that providing care to an older person may be related to impaired labour market participation. The consequences of caring can therefore include a reduced income (see Chapter 2, section 2.4.3). The findings showed that as many as thirty-three (22%) of the carers, the majority of whom were Gujarati and Punjabi (n=14, 42%; n=15, 45% respectively), perceived they did not have sufficient income to meet their needs. Given the findings on employment and the fact that, of those carers who did not feel they had enough income, the great majority were Asian (88%), it does appear that in socio-economic terms the Gujarati and Punjabi carers in this research fared less well than the white indigenous carers. The following section now takes a more detailed look at communication factors, which may, in part, have influenced some Asian carers' lower socio-economic status.

### **6.2.3 Communication Factors and Ethnicity**

Fluency in English may not only influence participation in the labour market, it is also considered a barrier to service uptake (Atkin and Rollings, 1993). Age, gender and age on arrival in the U.K. are important factors in determining an individual's level of ability in English language (Modood, 1997). As many of the younger generation would have grown up in Britain, it was interesting to find out which language the Gujarati and Punjabi carers considered to be their first language (see Q. 98, Appendix 1). The data showed that the great majority of Gujaratis and Punjabis viewed their community language as their first language (n=46, 92%; n=49, 98% respectively). However, four of the Gujarati carers and one Punjabi carer reported English as their first language. Further examination of the data revealed that

the majority of Gujarati and Punjabi carers viewed English, rather than any other Asian dialect, as their second language (n=42, 84% in both groups). This data accords with other research in that most South Asians belong to only one South Asian linguistic community (Modood, 1997), which is linked to their ethnic and/or religious community. Given that the majority of Gujarati and Punjabi carers view their community language as their first language, it is interesting to see whether this factor has any influence on their ability to communicate in English. As previously indicated, language barriers influence communication effectiveness with service providers (see Chapter 3, section 3.5.1). Carers were therefore asked whether they found they had language/communication problems with the formal agencies they dealt with (see Q.38, Appendix 1). Table 6.5 exhibits this information.

**Table 6.5 Communication Problems by Ethnicity and Gender**

Communication problems	Gujarati		Punjabi		Total
	M	F	M	F	
No problems	8 (16%)	24 (48%)	3 (6%)	9 (18%)	44 (44%)
Problems	2 (4%)	16 (32%)	8 (16%)	30 (60%)	56 (56%)
Base	50 (100%)		50 (100%)		100 (100%)

The table above demonstrates that almost two thirds of Gujarati carers (n=32, 64%), but only one quarter of Punjabi carers (n=12, 24%), did not consider themselves to have any communication problems with service providers. Clearly, there are differences between the language abilities of the Gujarati and Punjabi groups of carers. Hence, a chi-square test of association was employed to see if there was a relationship between communication problems and being a Gujarati or Punjabi carer. A highly significant chi-square test result (chi-square=16.23, df=1, p<0.001) indicated that the Punjabi group of carers experienced significantly more communication problems than the Gujarati carer group. One possible

contributory factor for this difference that was not recorded might be that many Gujaratis come from East Africa, which could be regarded as an English speaking region, whereas Punjabis originated in the Indian sub-continent.

Given that gender and age on arrival in the U.K. are influencing factors in fluency in English, it is revealing to examine the data in more detail. Table 6.5 exhibits the carers' gender in the Gujarati and Punjabi groups. It shows that four times as many Punjabi males experienced communication problems as Gujarati males ( $n=8$ , 16%;  $n=2$ , 4% respectively). Further examination of the data showed that six of these male Punjabi carers were aged 41-70 years and of these six, three had lived in Britain for 25 years or more. Since Asian men (particularly younger males) have more opportunity to increase their proficiency in English, which increases with time in this country, this finding does not accord with what one might have expected. One possible explanation for this might be the clustering of specific ethnic groups in particular neighbourhoods, resulting in a lower stimulus to be able to speak English fluently (Modood, 1997).

Table 6.5 shows that almost twice as many Punjabi female carers experienced communication problems with service providers as female Gujarati carers ( $n=30$ , 60%;  $n=16$ , 32% respectively). Further exploration of the data showed that in both of these groups the women were aged between 26-70 years. The determining factor here was that in the 26-40 year age group less than one third of the female Gujarati carers, yet almost two thirds of Punjabi female carers reported problems with communication ( $n=5$ ;  $n=13$  respectively). However, all these Gujarati females ( $n=5$ ) and the majority of the Punjabi females ( $n=10$ ) had lived in Britain for six years or more. It is fascinating to explore further the data to find a possible explanation for this difference. No major differences between these two female carers groups aged 26-40 years were found in terms of the number of young children they had, or in terms of the number of hours a day they were caring which would indicate less of

an opportunity to speak English outside the home. The one main factor that may account for this difference was that almost twice as many Gujarati as Punjabi women in this age group were able to combine their caring and household responsibilities with paid employment (n=12, 67%; n=7, 35% respectively). Hence, more female Gujarati carers than female Punjabi carers had a better opportunity to improve on their levels of fluency in English, which would enable them to have fewer communication problems with service providers. The final part of this section turns now to religious affiliation, which is another factor influential in ethnic identity.

#### 6.2.4 Religious Affiliation and Ethnicity

Religion is an important aspect in the self-definition of many South Asian people. In addition it helps to shape social networks and community organisation (see Chapter 3, section 3.3.2). Table 6.6 details the religious following of the three different cultural groups.

**Table 6.6 Religions Followed by Ethnicity<sup>5</sup>**

Religion	Gujarati	Punjabi	White	Total
C of E <sup>6</sup>	0	0	36 (75%)	36 (24%)
Hindu	45 (90%)	5 (10%)	0	50 (34%)
Jain	5 (10%)	0	0	5 (3%)
Moslem	0	7 (14%)	0	7 (5%)
Sikh	0	38 (76%)	0	38 (26%)
Other denominations	0	0	12 (25%)	12 (8%)
Base	50 (100%)	50(100%)	48 (100%)	148 (100%)

<sup>5</sup> Two of the white indigenous carers were Atheists and were therefore not included in the table.

<sup>6</sup> C of E denotes the Church of England.

Although the data demonstrate the many diverse religious affiliations of the groups, they also show that the large majority of Gujarati speaking carers are of the Hindu religion (n=45, 90%), and that three quarters of Punjabi speaking carers follow the Sikh religion (n=38, 76%). This information accords with other surveys which have shown that among Indians, Sikhs outnumber Hindus, but for those coming from Africa, such as Gujaratis, more follow the Hindu religion. This may constitute an important difference between them (Berthoud *et al.*, 1997). The religious following of the white indigenous group is more widely spread than for both the Gujarati and Punjabi carer groups, although almost three quarters of this group (n=36, 72%) report themselves as belonging to the Church of England (C of E). The findings regarding the white indigenous carers therefore do not support other work which has found that almost one third of white people have no religious affiliation (Modood, 1997). So far, the chapter has concentrated mainly on the carers. The following section now describes the characteristics of older people receiving their care.

### **6.3 Characteristics of Older People Receiving Care**

The focus of this thesis is on carers of older people. Nonetheless, it is also important to look at the older people receiving care and the involvement of their carers in that care. Before looking at the characteristics of older people receiving care there are two factors that should be pointed out. Firstly, all the older people were cared for by carers in their own ethnic group, otherwise they would not have been eligible for the study. Secondly, the information received was provided by the carers and not by the older people as it is the carer's perspective that is important in the understanding of their caring experience.

#### **6.3.1 Gender, Age and Ethnicity of the Cared-for Older Person**

In the first part of this section, it is informative to look at some demographic characteristics of the older people in receipt of care (see Table 6.7).

**Table 6.7 Gender, Age and Ethnicity of Older People Receiving Care**

Age Range	Gujarati		Punjabi		White		Total
	M	F	M	F	M	F	
55-75 years	14 (28%)	28 (56%)	12 (24%)	27 (54%)	5 (10%)	10 (20%)	96 (64%)
76-90 years	6 (12%)	2 (4%)	3 (6%)	7 (14%)	8 (16%)	21 (42%)	47 (31%)
91+ years	0	0	1 (2%)	0	2 (4%)	4 (8%)	7 (5%)
Base	50 (100%)		50 (100%)		50 (100%)		150 (100%)

The table shows that, of the one hundred and fifty older people being cared for, one third were men ( $n=51$ , 34%) and two thirds were women ( $n=99$ , 66%). Given that women have a greater life expectancy and outnumber men at all ages higher than fifty years of age (OPCS, 1983), it is not surprising that more older women than men in this study were in receipt of care. Table 6.7 also shows that almost two thirds of older people receiving care were in the youngest age group of 55-75 years ( $n=96$ , 64%). However, with the white group over two thirds were in the older age group of 76 years and over ( $n=35$ , 70%). The great majority of Gujarati and Punjabi older people receiving care were found in the younger age group of 55-75 years ( $n=42$ , 84%;  $n=39$ , 78% respectively), compared to just under a third of the older white people in this age band ( $n=15$ , 30%). A chi-square test on this data showed there was a significant association between age and ethnicity (chi-square=38.02,  $df=2$ ,  $p=0.000$ ). Clearly, the difference lies with the fact that older Asians were younger than white indigenous older people. Further examination of the data also showed that in terms of gender and age groups ethnic differences could still be discerned. Most of the older men and the great majority of women aged 55-75 years were Asian ( $n=26$ , 84%;  $n=55$ , 85% respectively), whereas half of the older males and the majority of females aged 76 years and above were white ( $n=10$ , 50%;  $n=25$ , 73% respectively). The data obtained from this study accords with other research which reports that, on average, minority groups have a higher incidence of disability and that such groups probably experience ill health and/or disability

at a younger age than the white indigenous population (Boneham, 1989; George, 1993; Ebrahim *et al.*, 1991). Therefore, the next step is to look at the nature of disability in the older people receiving care.

### 6.3.2 Older People and Disability

Carers were asked why the older person they were looking after needed support or care (see Q.90, Appendix 1). The questionnaire elicited a number of instances of ill health and physical disability/limitation. Given that many older people may have more than one health/disability problem, more than one disability per person was recorded. Table 6.8 demonstrates the nature of the health/disability problems of the older person receiving care. It shows that more than one disability existed for some of the older people, and indicates that more disabilities/limitations were reported for older white people than for older Gujaratis and Punjabis receiving care (n=72, 37%; n=65, 33%; n=57, 29% respectively).

**Table 6.8 General Disabilities in Older People by Gender and Ethnicity**

Disability	Gujarati		Punjabi		White		Total
	M	F	M	F	M	F	
Physical disability	17 (26%)	21 (32%)	10 (17%)	26 (46%)	13 (18%)	29 (40%)	116 (60%)
Sensory impairment	6 (9%)	10 (15%)	4 (7%)	11 (19%)	4 (5%)	11 (15%)	46 (24%)
Mental health problems	2 (3%)	8 (12%)	2 (3%)	3 (5%)	4 (5%)	11 (15%)	30 (15%)
Learning disability	0	1 (1%)	0	1 (2%)	0	0	2 (1%)
Base	65 (98%)		57 (99%)		72 (98%)		194 (100%)

Of all the disabilities listed, the majority of older people were reported to have a physical disability/limitation (n=116, 60%). No major differences in the incidence of physical

disability/limitation between the three cultural groups were discerned. Similarly, there were no real differences between the groups in those older people reported to have sensory impairment problems or have a learning disability.

Table 6.8 however does show some cultural differences in the occurrence of mental health disorders. More white older people (n=15, 20%) were reported to suffer from this problem than either the Gujarati group or the Punjabi group of older people (n=10, 15%; n=5, 8%). This discovery accords with the results of Cochrane and Stopes-Roe (1980) who found less reported mental illness among Asian immigrants. Nonetheless, a contributory factor might be that Asians perceive mental health problems as a social dysfunction (Rack, 1982), so there may be a reluctance to admit to a stigmatising mental illness. Other explanations for fewer reported incidences of mental health problems among the Asian community may also include inadequacies in diagnosis and treatment by health professionals employing a European model of medicine (Blakemore and Boneham, 1994). Not only do different patterns of health within and across cultural groups have implications for meeting the particular needs of different people, they also reflect the social position of these groups (Modood, 1997). Therefore, it now seems pertinent to explore the socio-economic position of the older people in receipt of care.

### **6.3.3 Socio-economic Position of Older People**

Carers in the sample were asked which financial benefits and pensions the older people they were caring for received. As indicated earlier, all of the material collected came from the carers themselves; therefore some carers, especially those caring for friends and neighbours, might not have the exact information regarding older people's income. In addition, given that the sample of carers were asked to indicate the age range of the older person beginning at 55 years and above (see Q.92, Appendix 1), it was not possible to control for the older person's exact age which may have been influential in their eligibility to benefits. Hence,

any information presented that is dependent on a specific age needs to be treated with caution.

Table 6.9 shows some of the variety of different benefits available to older people, which may be important in their ability to pay for, or contribute towards, the level of care they need (see Q.84, Appendix 1). Given that older people may have more than one source of financial benefit, more than one income was recorded.

**Table 6.9 Older People and Benefits Received by Gender and Ethnicity**

Benefits	Gujarati		Punjabi		White		Total
	M	F	M	F	M	F	
State retirement pension	13 (11%)	10 (8%)	7 (8%)	6 (7%)	13 (11%)	32 (27%)	81 (25%)
Private pension	1 (1%)	1 (1%)	0	2 (2%)	2 (2%)	8 (7%)	14 (4%)
Occupational pension	1 (1%)	0	1 (1%)	2 (2%)	3 (2%)	4 (3%)	11 (3%)
Disability pension	1 (1%)	0	2 (2%)	1 (1%)	1 (1%)	1 (1%)	6 (2%)
Income Support	15 (12%)	21 (17%)	11 (12%)	23 (26%)	2 (2%)	5 (4%)	77 (23%)
Attendance/ care allowance	11 (9%)	11 (9%)	4 (4%)	13 (15%)	8 (7%)	20 (17%)	67 (20%)
Mobility allowance	4 (3%)	11 (9%)	3 (3%)	7 (8%)	4 (3%)	9 (7%)	38 (12%)
Housing benefit	11 (9%)	9 (7%)	2 (2%)	4 (4%)	3 (2%)	5 (4%)	34 (10%)
Base	120 (98%)		88 (97%)		120 (100%)		328 (99%)

Table 6.9 clearly shows that more white older people than older Gujaratis, and especially older Punjabis were reported to receive much of their income from pensions and in

particular from the state retirement pension (n=45, 90%; n=23, 46%; n=13, 26% respectively). This finding can be attributed to the fact that more white older people than either Gujarati or Punjabi people in need of care were of a definite pensionable age (see Table 6.7).

The table demonstrates that five times as many Gujarati and Punjabi older people than white older people were reported to receive Income Support (n=36, 72%; n=34, 68%; n=7, 14%). These findings therefore tend to bear out the low socio-economic status of older Asians, who may have had little opportunity to work and build state pensions (particularly older Asian women) and who therefore may need to rely on means tested Income Support (Jadeja and Singh, 1993).

Following the discussion of some of the characteristics relating to carers and older people separately, the final section of this chapter now concentrates on both the carer and the older person together.

#### **6.4 Carers and Older People Receiving Care**

This part of the chapter is aimed at looking at the nature of care given to older people. It therefore begins by investigating the relationship of the carer to the older person for whom they are caring.

##### **6.4.1 Relationship of the Carer to the Cared-for Older Person**

The Griffiths Report (1988) promoted the view that families, friends and neighbours were the primary source of community support. Indeed, the family has long been the main source of care given to older people in need of care (Qureshi and Walker, 1989; Parker G., 1990; Parker, R., 1990), and the data gathered in this research supports this fact. Nonetheless, Griffiths (1988) also included friends and neighbours in the bedrock of community care. As

demonstrated by Tables 6.10 and 6.11, only eight of the carers were friends and neighbours (all females) and were caring for an older person who was not a member of their family. Tables 6.10 and 6.11 demonstrate the relationship between male and female older people and the gender of their carer across the three cultural groups.

**Table 6.10 Relationship of Male Cared-for Person to Carer**

Relationship of cared-for person to carer	Gujarati		Punjabi		White		Total
	M	F	M	F	M	F	
Male Spouse/partner	0	11	0	4	0	8	23 (15%)
Father	2	2	2	2	0	6	14 (9%)
Father-in-law	1	3	2	5	0	1	12 (8%)
Uncle	1	0	1	0	0	0	2 (1%)
Male Friend/neighbour	0	0	0	0	0	0	0
<b>Total</b>	<b>4</b>	<b>16</b>	<b>5</b>	<b>11</b>	<b>0</b>	<b>15</b>	<b>51 (33%)</b>

**Table 6.11 Relationship of Female Cared-for Person to Carer**

Relationship of cared-for person to carer	Gujarati		Punjabi		White		Total
	M	F	M	F	M	F	
Female Spouse/partner	3	0	4	0	8	0	15 (10%)
Mother	3	11	1	8	0	15	38 (25%)
Mother-in-law	0	13	1	17	0	5	36 (24%)
Aunt	0	0	0	0	0	1	1 (1%)
Grandmother	0	0	0	0	0	1	1 (1%)
Female Friend/ Neighbour	0	0	0	3	0	5	8 (5%)
<b>Total</b>	<b>6</b>	<b>24</b>	<b>6</b>	<b>28</b>	<b>8</b>	<b>27</b>	<b>99 (66%)</b>

The tables indicate that the majority of carers (n=99, 66%) were caring for a female older person of which the great majority were a female relative (n=91, 92%). More carers were caring for their mother than any other category (n=38, 25%). Table 6.11 shows that, across the three cultural groups, slightly more white indigenous carers than Gujarati or Punjabi carers were caring for their mother (n=15, 30%; n=14, 28%; n=9, 18% respectively). The next largest category of older people receiving care was that of the mother-in-law (n=36, 24%). Here, it can be seen that more Punjabi carers than Gujarati or white indigenous carers were caring for their mother-in-law (n=18, 36%; n=13, 26%; n=5, 10% respectively). These data therefore show that almost equal numbers of Gujarati carers were caring for their mother and mother-in-law (n=14, n=13 respectively). Twice as many Punjabis were caring for their mother-in-law as opposed to their mother (n=18, n=9 respectively), and three times as many white indigenous carers were caring for their mother as opposed to their mother-in-law (n=15, n=5 respectively).

Similarly, equal numbers of Gujarati carers were caring for their father and father-in-law (n=4). Almost twice as many Punjabis were caring for their father-in-law rather than for their father (n=7, n=4 respectively), and six white indigenous carers were caring for their father as opposed to only one carer looking after their father-in-law. These figures therefore tend to bear out that normative priorities involved in caregiving lie more with sons and daughters-in-law in South Asian culture than they do in western culture where daughters, rather than sons and daughters-in-law, tend to assume care for a parent (see Chapter 3, section 3.3.3). Nevertheless, the fact that equal numbers of Gujarati carers were caring for a parent and a parent-in-law indicate that these normative priorities may be changing. The data exhibited in Tables 6.10 and 6.11 also accord with other research, in that in relation to older people being cared for by a younger generation, daughters and daughters-in-law form the main locus of care (Townsend, 1957; Levin *et al.*, 1989; Parker, G., 1990). The following section of this chapter now looks at where the care to older people is provided.

#### 6.4.2 Situation of Care Provision to Older People

Carers in the sample were asked whether they cared for the older person in the same household, and if not, how far they lived from the older person they cared for (see Q. 92). There were two main reasons for asking this question. Firstly, it was interesting to investigate whether there were any cultural differences in family organisation, as extended family living arrangements have been associated more with Asian families than they have with the white indigenous population (Berthoud and Beishon, 1997). Secondly, it was pertinent to explore whether co-residency had any bearing on the different aspects of care provided by the carers.

The data collected show that two thirds (n=102, 68%) of carers were caring for an older person in the same household (see Table 6.12).

**Table 6.12 Care Provision to Older People in the Same Household or Elsewhere by Ethnicity**

Where care is provided	Gujarati	Punjabi	White	Total
Same household	38 (76%)	40 (80%)	24 (48%)	102 (68%)
Elsewhere	12 (24%)	10 (20%)	26 (52%)	48 (32%)
Base	50 (100%)	50 (100%)	50 (100%)	150 (100%)

Chi-square=13.97, df=2, p<0.001

Table 6.12 clearly shows that relatively more older Gujarati and Punjabi people than older white people were cared for in the same household as their carer (n=38, 76%; n=40, 80%; n=24, 48% respectively). A chi-square test on the data in Table 6.12 confirms that there was a highly significant association between co-residency and ethnicity. Proportionately more Gujarati and Punjabi than white indigenous carers were likely to co-reside than live elsewhere. This indicates that the extended family in South Asian communities strongly

exists in Britain today, although sample selection may have had a bearing on this outcome.

Table 6.13 shows the relationship of the older person to their carer in the three cultural groups and co-residency in more detail. It indicates some differences in co-residency and the relationship of the older person to their carer within the three cultural groups. Not surprisingly none of the friends or neighbours were co-resident with their carer, and all of the older people who were the spouse/partner, and who needed care, were looked after in the same household as their carer (see Tables 6.10, 6.11).

**Table 6.13 Residency and the Relationship of the Older Person to Their Carer by Ethnicity<sup>7</sup>**

Relationship of Older person to carer	Gujarati		Punjabi		White		Total
	Co	E	Co	E	Co	E	
Spouse/ Partner	14 (28%)	0	8 (16%)	0	16 (32%)	0	38 (25%)
Mother	9 (18%)	5 (10%)	7 (14%)	2 (4%)	5 (10%)	10 (20%)	38 (25%)
Father	2 (4%)	2 (4%)	3 (6%)	1 (2%)	0	6 (12%)	14 (9%)
Mother-in-law	11 (22%)	2 (4%)	17 (34%)	1 (2%)	0	5 (10%)	36 (24%)
Father-in-law	2 (4%)	2 (4%)	5 (10%)	2 (4%)	1 (2%)	0	12 (8%)
Other relative	0	1 (2%)	0	1 (2%)	2 (4%)	0	4 (3%)
Friend/ neighbour	0	0	0	3 (6%)	0	5 (10%)	8 (5%)
Base	50 (100%)		50 (100%)		50 (100%)		150 (99%)

The table shows that, for the white indigenous sample of carers, caring for the spouse/partner formed about one third of the care given (n=16, 32%). For Gujarati carers caring for one's spouse/partner constituted almost one third of care given. For the Punjabi carer group it formed less than one fifth of care given in the same household (n=14, 28%;

<sup>7</sup> Co denotes co-residency of the carer and the older person. E denotes that the older person lives elsewhere.

n=8, 16% respectively). Nevertheless, one might not necessarily expect carers to co-reside with parents, parents-in-law and wider family members who needed care. In this research three times as many Gujarati carers and four times as many Punjabi carers as white indigenous carers co-resided with these older people (n=24, 48%; n=32, 64%; n=8, 16% respectively). This indicates that Asian carers tend to care for a wider range of family members in the same home as themselves. This again demonstrates a strong cultural norm of caring for one's elders as part of the extended family.

**Table 6.14 Types of Help Given by the Same Household or Elsewhere<sup>8</sup>**

Help given	Same household	Elsewhere	Total	Chi-square	df	p
Personal care	58 (57%)	20 (42%)	78 (52%)	3.02	1	< 0.09
Physical help	74 (73%)	27 (56%)	101 (67%)	3.94	1	<0.05 *
Paperwork	88 (86%)	39 (81%)	127 (85%)	0.63	1	< 0.43
Practical help	100 (98%)	47 (98%)	147 (98%)	0.01	1	<0.97
Keeping X Company	100 (98%)	48 (100%)	148 (99%)	0.95	1	<0.33
Taking X out	93 (91%)	41 (85%)	134 (89%)	1.14	1	<0.29
Medical help	75 (73%)	21 (44%)	96 (64%)	12.56	1	<0.001*
Supervision	95 (93%)	45 (94%)	140 (93%)	0.02	1	<0.89
Base	102	48	150			

Table 6.14 examines whether the type of care given to the older person varies with residency. It shows that in almost all of the categories the majority of care was given to older people in the same household as their carer. Chi-square tests of association were employed to investigate the relationship between the type of help given, and residence of the

<sup>8</sup> \* denotes a significant result.

older person and their carer. This revealed there was a significant association in two of the eight categories. These were between physical help and co-residence (chi-square=3.94,  $df=1$ ,  $p<0.05$ ) and between medical help and co-residence (chi-square 12.56,  $df=1$ ,  $p<0.001$ ). Clearly, carers provided significantly more physical and medical help to older people who co-resided than to older people who lived elsewhere. There are two possible reasons for this. It could be either that older people needed extra physical and medical help, which had led to the need for co-residence, or the fact that they lived in the same household may have implied that this kind of help was given automatically. There was little difference in the other forms of help provided to older people in the same household or elsewhere. This is somewhat surprising as one might have thought that, for example, the provision of personal care and supervision would also have been provided more by co-resident carers than by those who lived elsewhere.

The data exhibited in Table 6.14 also show that fewer carers gave personal help to the older person than any other form of support ( $n=78$ , 52%). Almost all of the carers helped with practical tasks and keeping the older person company ( $n=147$ , 98%;  $n=148$ , 99% respectively). The forms of help listed in Table 6.14 were also included in the GHS (1990) where the amount of help given by carers ranged from 16% (for medical help) to 79% for practical help. In the present study, it thus appears that relatively more carers gave considerably more help than did carers in the GHS (1990). Caution is nevertheless needed in comparing the findings from the present research with those from the 1990 GHS data, as the carers in the GHS survey were caring for a wider range of dependants, and because the data on types of help given did not detail the age of the recipient. Nonetheless, over three-quarters (79%) of those receiving care in the 1990 GHS were aged 65 years and over. This therefore suggests that the older people receiving care in this study possibly needed more assistance than did the dependants in the GHS (1990). However, sampling methods may have contributed to the findings in this study, in that the use of community groups, known

carers, and snowballing methods meant that many of the older people receiving care were already known to have more acute needs.

Table 6.15 presents data on the type of help that was given by male and female carers (cultural differences pertaining to some of the forms of support provided will be examined in the following chapter). Chi-square tests of association were carried out on the types of help given by male and female carers. This analysis was restricted by the circumstance that the expected value for some of the cells was less than five. Overall, however, results revealed that there was no significant relationship between male and female carers and types of help given.

**Table 6.15 Types of Help Given to Older People by Carer Gender<sup>9</sup>**

Help given	Male	Female	Total
Personal care	14 (48%)	64 (53%)	78 (52%)
Physical help	19 (65%)	82 (68%)	101 (67%)
Paperwork	27 (93%)	100 (83%)	127 (85%)
Practical help	28 (96%)	119 (98%)	147 (98%)
Keeping X company	28 (96%)	120 (99%)	148 (99%)
Taking X out	29 (100%)	105 (87%)	134 (89%)
Medical help	20 (69%)	76 (63%)	96 (64%)
Supervision	26 (90%)	114 (94%)	140 (93%)
Base	29	121	150

From the data in Table 6.15, it can be seen that slightly more male carers than female carers took the older person out (n=29, 100%; n=105, 87%). One explanation for this might be that

<sup>9</sup> Percentages listed are the totals for each type of help given by male and female carers.

male carers possibly had more access to private transport than female carers. A few more male carers than female carers helped with paperwork (n=27, 93%, n=100, 83% respectively). This accords with the GHS (1985) where it was found that these were also the only two categories where a slightly higher percentage of male carers than female carers performed these tasks (males=41%, females=40%; males=53%, females=47% respectively). The explanation here might be that traditionally men tend to deal more with the administrative duties of running a household than women (e.g. Ungerson, 1987).

More female carers than male carers helped with personal care (n=64, 53%; n=14, 48% respectively). This finding also accords with the GHS (1985) data, in that more women than men helped with this task (males=19%, females=28%). It does therefore appear that the provision of personal care is more of a female domain (Twiggy and Atkin, 1994). In every other category of help given to older people by male and female carers in this research, there was little difference in gender and the type of help given. This indicates that many caregiving tasks are not necessarily gender related (e.g. Neal *et al.*, 1997). The penultimate section of this chapter now explores the time carers gave to their caregiving responsibilities.

### 6.4.3 Time Spent Caring

Carers were asked about how many hours per week they spent caring (see Q. 102, Appendix 1). Past surveys have shown that the provision of fewer hours of care per week (0-19 hours) is associated with carers who live elsewhere, whereas caring for more than 20 hours per week is associated more with co-resident carers (GHS, 1985, 1990). Table 6.16 tabulates the data on co-residence. Not surprisingly, the great majority of co-resident carers were more heavily involved- i.e. caring for more than 35 hours per week- than carers living elsewhere (n=77, 76%; n=10, 20% respectively). The cut-off of 35 hours per week is almost equivalent to full-time work- i.e. 37.5 hours per week)

The GHS (1990) reported that 40% of carers caring for someone in the same household devoted at least fifty hours per week to caring. Table 6.16 demonstrates that, in this sample of carers of older people, more co-resident carers than the GHS (1990) spent fifty hours or more per week caring (n=62, 61%). Again, one explanation for this difference may be the sampling method of carers in this study; as Table 6.14 above shows, the older people in this study appeared to have been provided with more assistance than the people receiving care in the GHS (1990). Therefore, it is also possible to assume that the carers would need to spend more time on their caring responsibilities.

**Table 6.16 Number of Hours Devoted to Caring per Week by Residency**

Hours caring per week	Same household	Elsewhere	Total
0-4 hours	1 (1%)	0	1 (0.7%)
5-9 hours	0	6 (12%)	6 (4%)
10-19 hours	11 (11%)	13 (27%)	24 (16%)
20-34 hours	13 (13%)	19 (40%)	32 (21%)
35-49 hours	15 (15%)	5 (10%)	20 (13%)
50-99 hours	15 (15%)	1 (2%)	16 (11%)
100+ hours	47 (46%)	4 (8%)	51 (34%)
Base	102 (101%)	48 (99%)	150 (100%)

Table 6.16 also demonstrates that the majority of non co-resident carers in this study spent over twenty hours per week on caring activities (n=29, 60%). This is more than found by the GHS (1990) where the majority of carers (69%) living in a different household were caring for less than ten hours per week. Again, this difference is probably due to sampling methods and the nature of the research, which may have inadvertently selected only older people who may have needed more help. The GHS (1985) found that the highest proportion of carers looking after someone in the same household for fifty hours or more per week were aged 65

years or over. Table 6.17 shows the age of co-resident carers in this study that were caring for fifty hours or more per week. It shows that most of the co-resident carers in this study who spent fifty hours or more looking after an older person were aged fifty-five years or younger (n=38, 61%). This was to be expected as three quarters of the carers were of this age group (n=113, 75%-see Table 6.2).

**Table 6.17 Age of Co-resident Carers Caring for 50 Hours or More per Week by Ethnicity and Gender**

Age of Carer	Gujarati		Punjabi		White		Total
	M	F	M	F	M	F	
18-40 years	1 (5%)	5 (25%)	2 (8%)	10 (42%)	0	0	18 (29%)
41-55 years	1 (5%)	7 (35%)	2 (8%)	7 (29%)	0	3 (17%)	20 (32%)
56-70 years	1 (5%)	4 (20%)	2 (8%)	1 (4%)	4 (22%)	4 (22%)	16 (26%)
71+ years	0	1 (5%)	0	0	3 (17%)	4 (22%)	8 (13%)
Base	20 (100%)		24 (99%)		18 (100%)		62 (100%)

Table 6.17 also demonstrates that most of the carers in this younger age group (55 years or under) caring for fifty hours or more per week were Gujaratis and Punjabis (n=14, 37%; n=21, 55% respectively). Again this was expected as the majority of carers aged fifty-five years or younger were Asian (Gujarati n=42, 37%; Punjabi n=42, 37% respectively). Clearly, the findings from this study cannot be directly compared to the GHS (1985, 1990) as the carers in these two surveys were caring for a wider range of dependants. Nonetheless, it would have been interesting to have an indication of the ethnicity of people defined as carers in these national surveys in order to have some type of comparative base in terms of age and gender. The final section of this chapter now explores the number of years the carers had been caring.

#### 6.4.4 The Number of Years Spent Caring

One of the early questions carers were asked concerned how long the older person had needed their care (see Q.3, Appendix 1), so that some comparison could be made with national surveys (e.g. the GHS, 1985). Overall, 17% of carers (n=25) had been looking after the older person in need of care for at least eleven years. The majority had been caring between one and five years (n=71, 47%). These findings are similar to the GHS (1985) which reported that 18% of carers had been caring for their dependant for at least ten years and a further 44% had cared for between one and four years. Table 6.18 details the information from this study across the three cultural groups.

**Table 6.18 Length of Time Caring by Ethnicity**

Length of care	Gujarati	Punjabi	White	Total
up to 1 year	6 (12%)	0	6 (12%)	12 (8%)
1-5 years	21 (42%)	27 (54%)	23 (46%)	71 (47%)
6-10 years	13 (26%)	18 (36%)	11 (22%)	42 (28%)
11+ years	10 (20%)	5 (10%)	10 (20%)	25 (17%)
Base	50 (100%)	50 (100%)	50 (100%)	150 (100%)

The table shows that there were some slight differences in the length of time given to caring across the three cultural groups. Although all three cultural groups had mostly cared for between one and five years (n=21, 42%; n=27, 54%; n=23, 46%), more of the Gujarati and white indigenous carers than the Punjabi carers had cared for eleven years or more (n=10, 20%; n=10, 20%; n=5, 10% respectively).

In terms of the relationship of the carer to the older person receiving care for eleven years or more, further examination of the data revealed that most of these were the carers' spouse or

mother-in-law (n=8; n=8 respectively,). In terms of co-residency and caring for the mother-in-law for eleven years or more, almost all of the Gujarati and Punjabi carers were living in the same household as their mother-in-law (n=7) whereas neither of the two white indigenous carers shared the same household as their mother-in-law. Again, one explanation for this finding could be the cultural differences in traditional family living arrangements.

## **6.5 Conclusion**

One of the main reasons for carrying out this research was the shift in focus on informal carers in community care initiatives. In addition, there was limited literature available on carers from different cultural groups. The findings from this chapter on the social and demographic characteristics of the sample have highlighted the paucity of both national and local data available on carer populations from different cultural groups. For instance, the GHS (1985) was designed to provide not only national estimates of carers, but also the numbers of carers in different sub-groups of carers in order to plan services to carers. Yet, it does not reveal the carers' ethnicity or the ethnicity of their dependant. Hence, it is not possible to gain a national view on carers from different cultural communities. Nonetheless, it has been possible to discern some similarities and differences in social and demographic characteristics between the three cultural groups and in relation to other research.

One of the main points gathered from this research has been the similarity in the numbers of male and female carers in the three cultural groups. In addition, in line with other surveys, more informal carers were female and, if caring for an older generation, were daughters or daughters-in-law. Hence, the carer's ethnicity does not appear to make any difference to the locus of care. Differences between the cultural groups showed that the Gujarati and Punjabi carers in this research tended to be significantly younger and were also caring for a significantly younger age group of older people. This finding therefore accords with the younger age profile of Asians in Britain and thus has implications for services to carers and

the older people they care for, in that Asians may need to care for a longer period of time than white indigenous carers. It was also found that significantly more Gujarati and Punjabi carers shared the same household and cared for a wider range of older people than did white indigenous carers. This finding shows that the extended family is still considered the norm with many Asian families, although sampling methods may have had a bearing on this in that more Asian co-resident carers were inadvertently selected.

One of the most striking and significant findings concerning the Gujarati and Punjabi carer groups was the fact that only one third of Gujarati carers, but three-quarters of Punjabi carers, experienced communication difficulties. This highlights the importance of monitoring carers' linguistic background as well as their ethnicity. Clearly, methods of providing information on available local services need to be geared towards a way in which they can be understood by carers from different cultural backgrounds. It also indicates the importance of balancing the needs of the local community with staff in formal agencies who are able to communicate in the same language.

The data collected and presented in this chapter indicate some interaction of factors between the three cultural groups, which will need to be controlled for in the subsequent analyses concerning perceived morale, stress and coping. The following two results chapters will now test the hypotheses outlined in Chapter Five by examining and discussing the psychosocial impact of caring on informal carers from different cultural backgrounds.

## CHAPTER SEVEN

### PERCEIVED MORALE AND STRESS IN CARERS

#### 7.1 Introduction

This chapter is concerned with the effect of caring on carers of older people. Findings were collated by the use of a semi-structured interview schedule. This method of investigation enabled the inclusion of psychometric techniques to measure carers' perceived morale and stress, as well as other quantitative and qualitative information to enhance the findings. Throughout the chapter the data is analysed in a thematic way against the hypotheses relating to the measures of perceived morale and perceived stress that were proposed in Chapter Five. Thus the statistical basis of argument can be put forward together with illuminating quotes given *ad verbatim* from the carers or as noted by the bi-lingual interviewers. This format of reporting permits a rigorous analysis of the issues against pre-supposed hypotheses, together with a sensitive consideration of the very personal feelings and experiences of the different groups of carers.

The chapter is divided into five main parts and it begins by looking at the motivations of carers to care. The objective here is to gain some insight into the benefits of caring and what initiates carers of older people from different cultural backgrounds to undertake their caring role (section 7.2). The chapter then moves on briefly to investigate the level of care provided by the carers, as the range and difficulty of activities they carry out are considered to be primary stressors affecting morale and the experience of stress (section 7.3). Following this, perceived morale levels in carers are examined with the use of psychometric techniques to assess their well-being (section 7.4). The next section then assesses perceived stress levels in carers (section 7.5). This is succeeded by an exploration of possible sources and nature of stress as defined by the literature and as reported by the carers in this study (section 7.6).

The growing recognition of informal carers has led to a better appreciation of carers' lives. There has, however, been little research on the motivations of carers to assume the responsibility to care. This first main section begins by looking at why carers care, as this may be an influencing factor in how carers view their role and find meaning in what they do. The perception of the caregiving activity may affect perceived levels of morale, the experience of stress and rewards associated with caring for an older person.

## **7.2 An Embracing Role: Carers' Motivation to Care**

The basis for carers' willingness to care depends on pre-existing conditions and relationships, which have helped to shape caring arrangements (Twigg and Atkin, 1994). Care is therefore embedded in social relationships (Pearlin *et al.*, 1990; Twigg *et al.*, 1990). For many carers caring for an older person is a natural process, for example they simply 'drift' into it (Lewis and Meredith, 1988:25); while for spouse carers it may be regarded as a continuation of a meaningful marital relationship (Motenko, 1989). On the other hand, there are other more conscious elements contributing to carers' willingness to care, such as not liking the idea of residential care or there being no-one else to look after the older person (Sinclair, 1990). Nonetheless, care is also largely based on factors such as personal ties and reciprocity (Harris, 1998; see also Chapter 2, sections 2.3, 2.4 and Chapter 4, section 4.3). Many carers thus regard the ability to care as a way of returning the love and affection they have previously enjoyed. The importance of this, in their readiness to assume the role of carer, can be illustrated by some of the comments made by carers during the interviews:

*She has lived with us for years. She helped me when the children were small. I love her like a mother. She is the priority now.*  
(female Gujarati caring for her mother-in-law)

*I've always had a close relationship with Dad. It's my way of being able to repay him.*

(female white indigenous carer)

*She has been such a good friend to me and helped me when I needed her. I am pleased to help her now.*

(female Punjabi carer of her friend)

The comments above clearly illustrate how feelings of love and affection for the older person can help to inspire caring arrangements. In addition, they help to demonstrate positive caring perceptions/rewards carers can gain from reciprocating for previous help (e.g. Harris 1998).

More recent work on caring has argued that there has been insufficient attention paid to the positive dimensions of caring. A focus on negative stressors and outcomes slants perceptions of the caring experience, thereby restricting the ability to improve carer adaptation (Kramer, 1997). Positive aspects of caring can include other sources of satisfaction, such as the rewards and benefits gained from the caring role as well as opportunities for learning new skills (Grant and Nolan, 1993). As expressed by one carer for whom new avenues had been opened up:

*I had to learn to drive to take Bill to hospital and doctors. It was hard at first, but I love it now. I feel like Stirling Moss.*

(female white indigenous carer looking after her husband)

In addition, some carers found that caring had the effect of extending their social life and giving them a new confidence:

*It has given me a new lease of life. I've met lots of different people. I go to lots of different places. I've learned how to travel and fend for myself.*

(female white indigenous carer of her husband)

The qualitative evidence reported by the carers in this study has already demonstrated how caring has led to greater closeness to the older person and provided an enhanced sense of meaning and pleasure in carers' lives. In addition, many carers reported that they had become more understanding of older people (n=70, 47%). A typical comment made by many of these carers was:

*I can see how people grow old and their problems. I get an insight into what it might be like for me. I enjoy listening to stories of the past.*

(female white indigenous carer of her mother)

The quotation above shows a dual function of caring for an older person. It shows not only how younger people can learn from the experience of older people, but also the value of reminiscence (e.g. Buchanan and Middleton, 1995). As pointed out by Coleman (1994), older people are important in the transmission of culture and tradition, which they can pass on to the younger generation by telling their life-story. For the Asian community, whose traditional customs have been disrupted by migration, this may be of special significance. As pointed out in Chapter 3 (see section 3.3.3), younger Asians, particularly those born and raised in Britain, are exposed to a diversity of attitudes, beliefs and values that may result in a diffusion of traditional Asian beliefs and cultural expectations. The transfer of beliefs, customs and cultural norms through reminiscence can therefore also help to reinforce the need to care for, and indeed the value of caring for, an older person. As expressed by one Gujarati carer looking after her mother:

*I think when you're brought up in an extended family you just accept the responsibility. Looking after and having an older person around is quite*

*normal in an Asian family. It also shows the next generation that looking after our parents is normal part of family life.*

The above quote helps to demonstrate that, as well as caring out of love and affection, many carers may also view their role as one of duty and obligation (see Chapter 3, section 3.3.3). These are not necessarily negative reasons to care, nor are they less important than love (see Chapter 2, section 2.4).

Caring out of love and obligation are both strongly motivating forces and the balance between the two is often difficult to establish (Lewis and Meredith, 1988). Though caring out of love or duty are not necessarily mutually exclusive, it may mean that some carers care because they feel obligated to care rather than actually making a free choice to do so. This means that some take on the caring role even when it is against their own interests and, as such, this can affect their feeling of well-being. Given that relationships and personal ties are important factors in assuming the role to care for an older person, it becomes interesting to investigate whether there is any difference in caring mainly out of love or duty for a spouse/partner, other relatives and/or friends/neighbours. All carers were therefore initially asked why they cared by responding to one of five broad categories (duty, obligation, family pressure, cultural norms and love (see Q.6, Appendix 1)). This information was then dichotomised into love or duty and cross tabulated with their relationship to the older person (love was classified on its own and all the other categories were grouped together as duty).

Table 7.1 shows that a similar number of carers reported that they cared mainly out of love (n=77, 51%) as out of duty (n=73, 49%).

**Table 7.1 Motivations for Caring by Caring Relationship<sup>10</sup>**

Relationship of the carer to the older person	Motivations for caring		
	duty	love	Base
Spouse/partner	14 (37%)	24 (63%)	38 (100%)
Mother	12 (32%)	26 (68%)	38 (100%)
Father	6 (43%)	8 (57%)	14 (100%)
Mother-in-law	30 (83%)	6 (17%)	36 (100%)
Father-in-law	6 (50%)	6 (50%)	12 (100%)
Other relative	3 (75%)	1 (25%)	4 (100%)
Friend/neighbour	2 (25%)	6 (75%)	8 (100%)
<b>Total</b>	<b>73 (49%)</b>	<b>77 (51%)</b>	<b>150 (100%)</b>

Closer examination of Table 7.1 nevertheless reveals some differences: love is more common than duty as a motive for caring for a spouse/partner (n=24, 63%; n=14, 37% respectively), for a mother (n=26, 68%; n=12, 32% respectively) and for a friend (n=6, n=2 respectively). However, carers were more likely to report duty as the main motive for caring for their mother-in-law (n=30, 83%, n=6, 17% respectively) and for other relatives such as aunt, uncle and grandparents (n=3, 75%, n=1, 25% respectively). These results therefore appear to demonstrate that, although the feelings of caring out of both love and duty may not necessarily be mutually exclusive, the more distant the personal bond between the older person and the carer, the less likely they are to express feelings of love. Ungerson (1987) also found in her small study of nineteen carers that, the closer the family relationship and feelings of love, the more carers expressed caring out of love, thus echoing these findings.

<sup>10</sup> Percentages listed are those for each category of relationship of the carer to the older person.

Against this background, it is worth investigating to see whether there are any cultural differences in the reported motives for caring (see Table 7.2).

**Table 7.2 Motivations for Caring by Ethnicity**

Motivations	Gujarati	Punjabi	White	Total
Duty	35 (70%)	30 (60%)	8 (16%)	73 (49%)
Love	15 (30%)	20 (40%)	42 (84%)	77 (51%)
Base	50 (100%)	50 (100%)	50 (100%)	150 (100%)

chi-square=33.04, df=2, p<0.0001

As the table above shows, there is a link between caring mainly out of love and duty and ethnicity. The majority of the Gujarati carers and most of the Punjabi carers (n=35, 70%; n=30, 60% respectively) reported they cared mainly out of duty, whereas an overwhelming majority of the white indigenous carers (n=42, 84%) reported they cared mainly out of love. This is an informative finding, which clearly indicates a significant difference in motivations to care between Asian and white carer groups. The data were further explored to see, firstly, whether the relationship of the carer to the older person being cared for and their ethnicity had any bearing on these findings. The curiosity here was generated by the fact that half of the Punjabi carers (n=25, 50%) and one third of the Gujarati carers (n=17, 34%), but only just over a tenth of white indigenous carers (n=6, 12%), were caring for a parent-in-law. Similar numbers of Gujarati and white indigenous carers were caring for their mother (n=14, 28%; n=15, 30% respectively) and spouse/partner (n=14, 28%; n=16, 32% respectively). Only nine (18%) Punjabi carers were caring for their mother and eight carers (16%) for their spouse/partner (see Tables 6.10, 6.11). Cultural norms for Asian daughters-in-law mean that, in effect, it is they who actually care for their in-laws, and this may therefore affect the way

Asian female carers feel about the motivation to care (see Chapter 3, section 3.3.3). Hence, it is also necessary to investigate whether the gender, ethnicity and relationship of the carers and the cared-for had any bearing on whether carers cared more out of duty than love.

Table 7.1 showed that caring for a spouse/partner, mother, father and friends/neighbours, was done more out of love than duty, whereas the reverse was true for the mother-in-law and other relatives. Chi-square tests were carried out of the association between ethnicity and motivations for caring on the seven different categories of relationship. Again, this analysis was limited because the expected frequencies were insufficient in the great majority of cases (more than 20% of the cells had an expected value of less than 5). Results did, however, reveal a significant association where caring for a spouse/partner was concerned as shown in Table 7.3.

**Table 7.3 Motivations for Caring for the Spouse/Partner by Ethnicity**

	Gujarati	Punjabi	White	Total
Duty	9 (64%)	3 (37%)	2 (12%)	14 (37%)
Love	5 (36%)	5 (62%)	14 (87%)	24 (63%)
Base	14 (100%)	8 (99%)	16 (99%)	38 (100%)

chi-square=8.61, df=2, p<0.02

The significant chi-square test demonstrated that caring for the spouse/partner by the white indigenous group was associated more with love rather than duty (n=14, 87%) than either the Gujarati or Punjabi carers (n=5, 36%; n=5, 62% respectively). This is an illuminating finding as one might assume there are strong personal bonds between spouses/partners whatever the cultural background. Another explanation might be that the language of caring used by carers to express their motivation to care differs between the different cultures.

Interestingly, more Gujarati (n=9) than Punjabi carers (n=3) said they cared more out of duty than love for their spouse/partner. One comment often made by female Gujarati carers during the interview was:

*It is my duty to look after my husband. He has been a good husband to me and a good father to the children.*

Although these carers undoubtedly also had feelings of love for their spouse/partner, it does appear that the Gujaratis in this project tended to think more in terms of a duty to care than did the Punjabis. It would be informative to conduct further research to try to isolate any cultural and linguistic traits in the language of caring in different South Asian communities.

Interestingly, the great majority of carers in all three cultural groups reported that they cared more out of duty than out of love for their mother-in-law (Gujarati n=13, 100%; Punjabi n=13, 72%, white indigenous n=4, 80%). The implication is that caring for one's mother-in-law is seen to be more one of duty and, that this perception is not culture specific. The lack of a personal bond and feelings of love between the carer and the older person may be an influencing factor in this outcome.

Further exploration of the data to see whether there was any relationship between carer gender, ethnicity and motivations to care could not be performed due to low numbers in the male carers. However, there was a significant association between female carers, their motivations to care and ethnicity as shown in Table 7.4.

Table 7.4 shows some distinct differences between the three female carer groups and their motivations to care.

**Table 7.4 Female Carers and Motivations for Caring by Ethnicity**

Motivations	Gujarati	Punjabi	White	Total
Duty	29 (72%)	26 (67%)	7 (17%)	62 (51%)
Love	11 (27%)	13 (33%)	35 (83%)	59 (49%)
Base	40 (99%)	39 (100%)	42 (100%)	121 (100%)

chi-square=31.04, df=2, p<0.0001

The difference between the female carers in the three cultural groups clearly derives from the fact that the majority of the white indigenous carers said they cared more out of love for the older person (n=35, 83%), whereas most of female Gujarati carers (n=29, 72%) and most of the Punjabi group of carers (n=26, 67%) reported that they cared more out of duty. Ungerson (1987) found that female carers spoke about norms and obligations based on their religious belief, and that religion was a determining factor in their motivation to care. This may be true of the Gujarati and Punjabi carers in the present study.

Given that religion plays a major role in the identity of South Asians, this may also help to provide an explanation for this difference in the way female white indigenous, Gujarati and Punjabi carers express their motivation to care. The significant results from the chi-square tests of association so far show that, on the whole, white indigenous carers assumed care for the older person more out of love than either the Gujarati or Punjabi carers who reported caring more out of duty. As indicated, there may be several different cultural factors that could influence the way these groups express the need to care, which warrant further investigation. Having looked at what motivates carers to care, the chapter now moves on to examine what carers actually do for the older person.

### 7.3 The Level of Care Provided by Carers

For carers, it is who they are caring for and the particular needs of the older person that has an impact on the type and amount of care they provide. For instance, looking after a neighbour who needs more general help, rather than a spouse who requires more intense and personal support, means that the nature of care will be different as will the levels of dependence upon the carer. In this study, only eight carers were providing help to friends/neighbours. The vast majority were caring for relatives (n=142, 95%) of which almost three quarters (n=102, 72%) were co-resident (see Tables 6.10, 6.11, 6.12). It is now widely recognised that informal carers provide a substantial amount of care and experience a level of physical exertion far above that experienced by others (Parker, 1990). Therefore, it becomes pertinent to look at the different types and amounts of personal, physical and practical help provided by the carers in this study (see Q.8, Appendix 1). In order to gain an overall view of the level of this general support regularly given by the three groups of carers, the nine different kinds of tasks they carried out were collated. Individual scores were then divided into three categories of low levels of support (1-4 tasks), medium levels of support (5-7 tasks) and high levels of support (8-9 tasks).

**Table 7.5 Carers' Levels of Support by Ethnicity**

Levels of support	Gujarati	Punjabi	White	Total
Low	11 (22%)	3 (6%)	1 (2%)	15 (10%)
Medium	25 (50%)	16 (32%)	22 (44%)	63 (42%)
High	14 (28%)	31 (62%)	27 (54%)	72 (48%)
Base	50 (100%)	50 (100%)	50 (100%)	150 (100%)

chi-square=19.78, df=4, p<0.001

Table 7.5 demonstrates that almost one half of carers (n=72, 48%) provided a high level of support. Slightly fewer carers provided medium levels of support (n=63, 42%), but only one tenth provided a low level of support and almost three quarters of these were Gujarati carers (n=11, 73%). Looking further at the different cultural groups one can see that the majority of Punjabi carers provided high levels of support (n=31, 62%), followed by the white indigenous carers (n=27, 54%), whereas only a small number of Gujarati carers provided this amount of care (n=14, 28%). A chi-square test revealed that the association between ethnicity and levels of support was highly significant (chi-square=19.78, df=4, p<0.001). The difference here clearly lies between the Gujarati group, who provided lower levels of support, and the Punjabi and white indigenous groups who provided higher levels of support. This is an interesting finding in that older Punjabis were reported to have fewer health and limitation/disability problems than either the older Gujarati or white indigenous older people (see Table 6.8). One explanation for this discrepancy may be that, as shown by Parker and Lawton (1994), involvement in some caring activities were more likely to imply a high level of involvement across the whole range of tasks. The need for, say, personal and physical care, would indicate further needs such as giving medicines. In light of these results, it is pertinent to look closer at the psychosocial impact of caring. Perceived morale will be examined first.

#### **7.4 Morale Levels in Carers**

Morale can be described as an individual's outlook towards the way they feel about themselves and their life. Satisfaction with the carer role and self-esteem therefore form the basis for a view of personal well-being (Pearlin *et al.*, 1990). In order to provide a broader picture of how carers felt about themselves and their caring role, some of the thoughts voiced by the carers during the interviews are presented first. This is followed by an examination of carers' perceived level of morale in the three cultural groups.

Qualitative evidence gathered during interviews with the carers understandably reveal both positive and negative feelings towards caring, which reflects the fact that people experience both positive and negative emotions as a part of caring (Kramer, 1997):

*She helps my emotional health. She keeps me sane. I can talk to her about my life and she gives me strength to carry on.*

(female white indigenous carer of neighbour)

For this particular carer, although busy with a young family, she felt that she was able to care and thereby enjoy a closer relationship with someone that boosted her feeling of well-being. It also demonstrates how the older person's life experience was used to help a younger, less experienced person, thereby highlighting that caring can also be a mutually beneficial relationship where the contributions and competencies of both parties are valued (Lewis and Meredith, 1988).

For other carers, being with the older person was so much a part of their life that without them their life would have been meaningless. This was particularly likely to be the case for married couples:

*Without him I would not want to live. I don't care what I need to do for him. He is my life.*

(Gujarati spouse carer)

*We have always done everything together. We rely on each other for company. I can't imagine life without her.*

(white indigenous spouse carer)

The above quotations demonstrate how a longstanding close relationship, as found in marriage, can bring a deeper understanding and appreciation of a spouse (Parker, 1993), thereby enhancing the way the carer views their situation.

On the other hand, the need to care within marriage could be emotionally draining, resulting in a less positive attitude towards caring and a poor sense of well-being:

*I have lost my marriage. My wife and I can't communicate. I feel very depressed now and I worry about the future.*

(male white indigenous carer)

Non-spouse carers also experienced such negative feelings towards the caring role, which may influence levels of morale, particularly when caring for an in-law:

*I am taken for granted. I am expected to do the cooking, cleaning and to look after mother-in-law. I have no sympathy from family. Sometimes my husband would ask about me, but then he would have more sympathy with mother-in-law and have very little for me. I get very tired and sometimes very, very unhappy.*

(female Punjabi carer)

The above quotes clearly demonstrate a variety of different feelings towards the caring role that are held by carers in general. In order to see how this information can be related to carers' levels of perceived morale in the three cultural groups, morale scores were collated and used to test hypothesis 1 stated in Chapter Five.

***Hypothesis 1:***

*the level of perceived morale will significantly differ between informal carers in the Gujarati, Punjabi and white indigenous carer groups researched.*

In order to test hypothesis 1, information regarding the carers' level of general morale was obtained by asking carers to indicate where they would place themselves on Cantril's Ladder (1965) (see Chapter 5, section 5.6.5; and Appendix 1, section 7). Scores

can range from 1 to 10 on the ten rungs of the ladder with 1 representing the lowest possible level of morale and 10 representing the highest level of morale. Morale scores for the sample as a whole ranged from 1 to 10. In terms of the three cultural groups, the Gujarati and the white indigenous groups registered across the whole range of possible morale scores. The morale scores of the Punjabi group only ranged from 1 to 8, thus indicating that none of the Punjabi carers perceived very high levels of morale. For the sample as a whole (n=150) results showed a mean morale score of 6.24. At this point it is interesting to compare the mean morale score of this study on carers of older people with that of another study which used the same measure on middle aged white people (45-69 years) who, because of their age, were also likely to be caring for an older person.

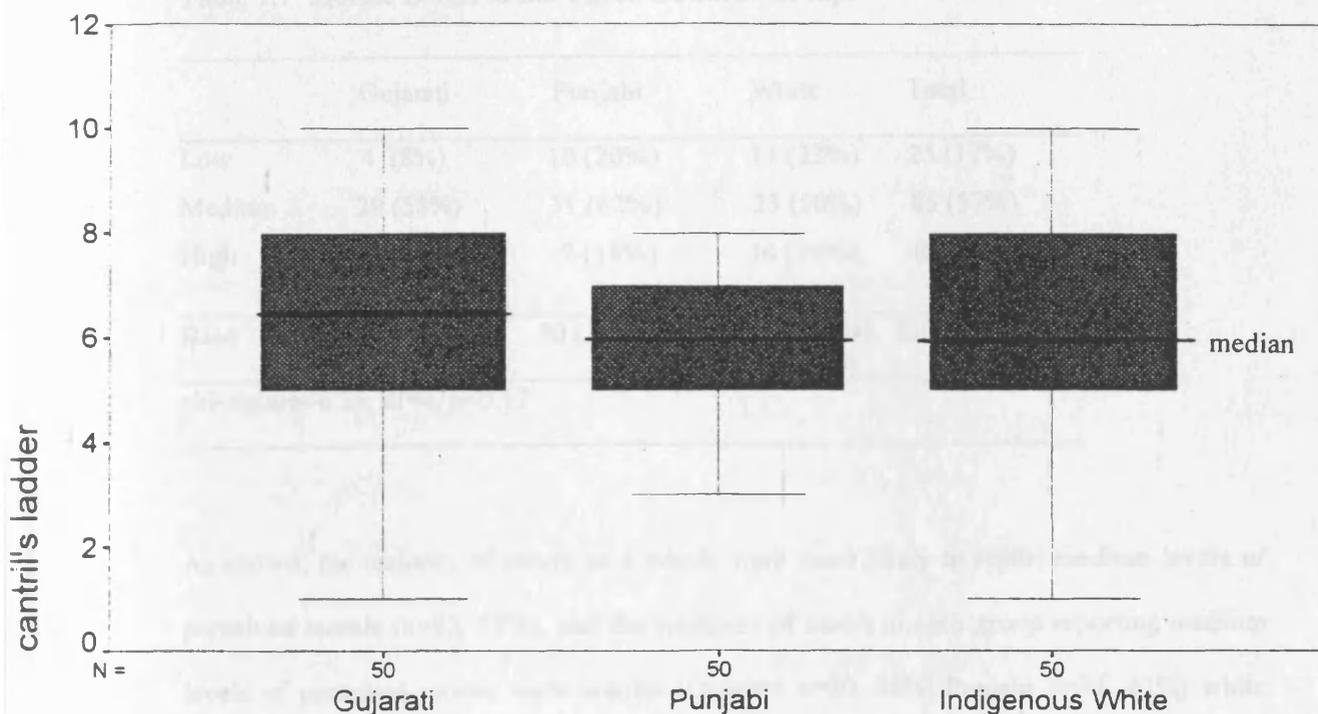
**Table 7.6 Comparison of Mean Morale Scores**

	Mean ( $\mu$ )	n
This study (Carers of older people)	6.24	150
Palmore and Luikart (1972)	7.0	502

Table 7.6 demonstrates that the mean morale score for this study is slightly less than for the Palmore and Luikart (1972) study researching middle aged white people. Although the present study included younger South Asian carers, the majority of carers were aged 41-70 years (n=88, 59%). The findings generated by this research therefore tend to indicate that, overall, morale levels in carers of older people are not that different to other populations of people who may or may not have been caring for an older person and report medium levels of morale. Differences between the three groups in this research will be examined in more detail next.

An initial exploration of the morale scores from all three groups indicated a non-normal distribution. This information limits future analyses to the use of median scores and non-parametric statistical tests. In order to look for differences between the three cultural groups, a box plot chart was generated. Figure 7.1 exhibits this information.

**Figure 7.1 Median Morale Scores for the Three Cultural Groups**



#### definition of ethnicity

The figure shows the range and spread of the scores in addition to the different position of the median morale scores for the three cultural groups. It shows that the Gujarati group of carers reported slightly higher median scores of perceived morale than did the Punjabi and white indigenous samples, who both shared the same median (median=6.5, 6.0, 6.0 respectively). Looking at the medians one can see that there is very little difference between the three cultural groups and a one-way analysis of variance on the ranked data on morale

between the three groups confirmed there was no significant difference ( $F=1.91$ ,  $p<0.15$ ). Given that carers had both positive and negative as well as uncertain perceptions of morale and their caring role, the scores from 0-10 obtained from Cantril's Ladder were classified into three categories: i.e. low perceived morale ranging from rungs 1-3; medium, i.e. uncertain perceived morale ranging from 4-7; and high perceived morale ranging from 8-10 (see Table 7.7).

**Table 7.7 Morale Levels in the Three Cultural Groups**

	Gujarati	Punjabi	White	Total
Low	4 (8%)	10 (20%)	11 (22%)	25 (17%)
Medium	29 (58%)	31 (62%)	25 (50%)	85 (57%)
High	17 (34%)	9 (18%)	14 (28%)	40 (27%)
Base	50 (100%)	50 (100%)	50 (100%)	150 (101%)

chi-square=6.55, df=4,  $p<0.17$

As shown, the majority of carers as a whole were more likely to report medium levels of perceived morale ( $n=85$ , 57%), and the numbers of carers in each group reporting medium levels of perceived morale were similar (Gujarati  $n=29$ , 58%; Punjabi  $n=31$ , 62%; white  $n=25$ , 50%). Carers as a whole also reported more high levels of perceived morale than they did low levels of perceived morale ( $n=40$ , 27%;  $n=25$ , 17% respectively). Although the data suggest some differences, a chi-square test did not reveal any significant difference between the three cultural groups (chi-square=6.55, df=4,  $p<0.17$ ). Nonetheless, the most interesting factor about the data in Table 7.7 is the apparent variation between perceived high and low morale scores in Gujarati and Punjabi carers. Almost twice as many Gujaratis as Punjabis reported high levels of morale ( $n=17$ , 34%;  $n=9$ , 18%) and over twice as many Punjabis as Gujaratis reported low levels of morale ( $n=10$ , 20%;  $n=4$ , 8% respectively).

Past research has shown that self-rated health is the strongest variable related to morale (Palmore and Luikart, 1972). Hence, it was interesting to see if the carers' perceived health had suffered through caring, which might help to explain the variation in the levels of morale in the three groups, and particularly between the Gujarati and Punjabi carer groups (see Qs. 18 and 19, Appendix 1). Given that the link between caring and emotional problems appears to be much clearer than between caring and physical health problems (Spackman, 1991), a chi-square test was employed on the data concerning carers' perceived emotional health and levels of morale.

**Table 7.8 Perceived Emotional Health by Levels of Morale**

Emotional health affected	Low	Medium	High	Total
Yes	23 (92%)	53 (62%)	15 (37%)	91 (61%)
No	2 (8%)	32 (38%)	25 (62%)	59 (39%)
Base	25 (100%)	85 (100%)	40 (99%)	150 (100%)
chi-square=19.38, df=2, p=0.000				

Table 7.8 demonstrates a significant association between the carers' emotional health and morale. It shows that the vast majority of carers who perceived low levels of morale also felt that their emotional health had suffered as a result of caring (n=23, 92%). Most carers who perceived medium levels of morale also felt that caring had negatively affected their emotional health (n=53, 62%). However, almost two thirds of carers who perceived high levels of morale did not think their emotional health had been adversely affected through caring. This finding accords with previous work and demonstrates the link between emotional health and morale (Palmore and Luikart, 1972). As there is a significant association between perceived emotional health and perceived levels of morale in the carers

in the present study, it is interesting to investigate whether perceptions of emotional health vary with ethnicity.

**Table 7.9 Perceived Emotional Health through Caring by Ethnicity**

Emotional health affected	Gujarati	Punjabi	White	Total
Yes	20 (40%)	36 (72%)	35 (70%)	91 (61%)
No	30 (60%)	14 (28%)	15 (30%)	59 (39%)
Base	50 (100%)	50 (100%)	50 (100%)	150 (100%)

chi-square=13.47, df=2, p<0.002

Table 7.9 shows that there is a significant association between perceived emotional health and ethnicity. Almost three quarters of the Punjabi and white indigenous carer group perceived that their emotional health had been negatively affected by caring (n=36, 72%; n=35, 70% respectively). In contrast, only two fifths of Gujarati carers (n=20, 40%) felt their emotional health had suffered as a result of caring. This finding accords with the fact that Gujarati carers reported higher perceived levels of morale. One possible explanation is that Gujarati carers gave significantly lower levels of care than Punjabi and white indigenous carers (see Table 7.5) and would therefore not perceive that their emotional health had suffered as a result of caring. The difference in carers' perceived emotional health and morale was also noticeable by the way they described how they felt:

*I'm feeling very, very sad. There is no happiness in me. My children have gone away. I have no one to talk to. I feel all alone.*

(female Punjabi carer of her husband)

*There is much pressure on me. I have to work early in the morning and late at night. I am tired, so tired I cry. She is always asking for me to do things. I do this to please my husband.*

(female Punjabi carer of her mother-in-law)

*I don't have the energy I used to. The doctor thinks I'm depressed and has given me some pills to take, but I don't feel they're helping me. I try to see the positive side of things, but somehow there seems no hope.*

(female white indigenous carer of her husband)

as opposed to the more positive comments made by female Gujarati carers:

*I think I have grown closer to my husband since he became ill. We have a good relationship, better than before.*

(female Gujarati carer)

*I am happy looking after mother. We get on well. I don't have any problems.*

(female Gujarati carer)

The above quotations demonstrate the different feelings regarding how these two groups felt about themselves and their caring role. Hence, as with previous work on self-esteem and caregiving, levels of perceived morale may be linked to the way carers actually feel about their caring role as part of their everyday lives (e.g. Pearlin *et al.*, 1990).

The quantitative data and subsequent analyses do not support hypothesis 1 concerning levels of perceived morale between the three different cultural groups. Nonetheless, the qualitative information does indicate some differences in perceived morale in the three carer groups. In addition, although there was no significant association in the levels of perceived morale between the Gujarati, Punjabi and white indigenous carer groups, there was a significant

association between ethnicity and perceived emotional health. The latter was also significantly related to morale (chi-square=19.38, df=2,  $p<0.000$ ).

There is no direct evidence to support hypothesis 1 concerning a difference in levels of morale between the three different cultural groups of carers. However, a possible link between the cultural groups and perceived emotional health through caring has been suggested. Therefore it is interesting to explore another measure of emotional health, namely that of stress, which also features in previous literature on caring. The next two sections of this chapter focus on how the carers in this study may experience stress.

### **7.5 Perceived Stress Levels in the Carers Researched**

Many studies researching carers have associated the experience of stress or emotional strain with caregiving responsibilities (e.g., Cantor, 1983; Lewis and Meredith, 1988; Russell *et al.*, 1989; Matson, 1994; Cossette *et al.*, 1995). Given the central role of informal carers in the success of community care, their emotional and physical health in terms of perceived morale and stress is important if only on a pragmatic level, in that it may affect their capacity to care.

Carers are individuals; thus their personalities, character and backgrounds as well as their circumstances will vary accordingly, as will their experience of stress. In order to compare the perceived stress levels between the different cultural groups carers were firstly asked to respond to a five point scale of perceived stress (from not stressed (1)<sup>11</sup> to very stressed (5), see Q.21, Appendix 1).

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<sup>11</sup> Numbers in brackets correspond to the score on the five point rating scale.

**Table 7.10 Perceived Stress in the Three Cultural Groups**

	Gujarati	Punjabi	White	Total
Not stressed	26 (52%)	6 (12%)	10 (20%)	42 (28%)
Not very stressed	4 (8%)	12 (24%)	10 (20%)	26 (17%)
Neither	12 (24%)	14 (28%)	10 (20%)	36 (24%)
Quite stressed	5 (10%)	12 (24%)	11 (22%)	28 (19%)
Very stressed	3 (6%)	6 (12%)	9 (18%)	18 (12%)
Base	50 (100%)	50 (100%)	50 (100%)	150 (100%)

Results revealed that over one quarter of the sample (n=42, 28%) did not perceive stress in their caring role. Less than two tenths perceived a little stress (n=26, 17%). Only one quarter of the sample were uncertain of their experience of stress (n=36, 24%), and almost one third reported feeling either quite stressed or very stressed (n=46, 31%). In terms of the three cultural groups, further exploration of the five point scale showed that the highest number of carers reporting perceived levels of stress were the Punjabi carers (n=44, 88%), followed by the white indigenous group (n=40, 80%) and finally the Gujarati carers (n=24, 48%). The findings from the five point perceived stress scale therefore suggest not only that many carers may sense the experience of stress as a result of their caring responsibilities, but also that the experience of stress differs in the three cultural groups. This can also be demonstrated by comments made by carers during the interview:

*There is a lot of pressure. Not just from looking after my husband, also from the rest of the family. It is only because they are worried.*

(female Punjabi carer)

*As well as going to work, I get stressed looking after Dad. Then there's the family who need me. I don't get a minute to meself.*

(female white indigenous carer)

*I try very hard to balance all the things I need to do. I do feel stressed, but I try to control myself.*

(female Gujarati carer of her mother)

*Yes, I'm completely stressed out. She is driving me mad. I feel like just getting up and leaving her.*

(male white indigenous carer of his wife)

The evidence from the quotes above and the five point scale clearly show that carers in all three groups perceived stress. Hence, it is now pertinent to examine this information against hypothesis 2 stated in Chapter Five.

### ***Hypothesis 2***

*the level and experience of perceived stress will significantly differ between informal carers in the Gujarati, Punjabi and white indigenous carer groups researched.*

In order to investigate hypothesis 2, the Malaise Inventory (Rutter *et al.*, 1970), which assesses psychosocial well-being, was used as an objective measure of stress. This particular measure of stress has also been applied in previous carer studies (Quine and Pahl, 1985; Quine and Charnley, 1987; Nolan and Grant, 1989; Bose, 1991; and see Chapter 5, section 5.6.5 for justification of use).

Some cultural differences in how carers described the physical and psychological symptoms were apparent by a closer examination of the data. Gujarati carers reported more feelings of tension and suffering from headaches. Punjabi carers felt particularly under pressure by the impact of caring on their daily lives. Here, 'pressure on the brain' was used by both groups to describe these feelings. The white indigenous group reported a wider range of symptoms that also included the experience of being tense and under pressure as well as frustration

and feeling easily irritated. The different ways carers perceived the experience of stress are demonstrated by these comments:

*I suffer with many headaches. It is like a pressure on the brain. They are worse since my mother has not been so well.*

(male Gujarati carer of his mother)

*There is much pressure on the brain. My mother does not seem to understand I also need to look after my husband and my children. I get very tired.*

(female Punjabi carer of her mother)

*I do feel tense and irritated by my father's behaviour. I'm only trying to do my best for him. He can be so difficult.*

(female white indigenous carer of her father)

*I feel much pressure on the brain. The doctor, he says I'm depressed.*

(male Punjabi carer of his father)

Many of the symptoms of perceived stress described above were similar to the items used to measure psychosocial aspects of well-being in the Malaise Inventory. Physical symptoms described by both male and female carers included headaches, indigestion, tiredness and a perceived deterioration in their general physical health. Emotional/psychological responses ranged from experiencing a loss in concentration, feeling easily upset and unhappy to being very anxious, feeling numb and the extremes of suicidal impulses. A correlation on the scores of perceived stress from the five point scale and this latter objective measure showed a strong positive association (Spearman's  $Rho=0.48$ ,  $p=0.000$ ). Further analyses of stress will, therefore, concentrate on the data obtained from the Malaise Inventory.

In comparison to perceived levels of psychosocial well-being on the five point scale, over twice as many carers were found to report stress ( $n=46$ , 31%,  $n=97$ , 65% respectively).

Further investigation of the data obtained from the Malaise Inventory showed a mean malaise score of 6.72 for the population as a whole, and in accordance with other carer studies, a cut off point of 5 and above on the Malaise Inventory was considered indicative of stress (Quine and Charnley, 1987; Nolan and Grant, 1989; Bose, 1991). At this point it is interesting to compare the mean malaise scores of this study on carers of older people to that of other studies on carers who have also used the same measure of stress.

**Table 7.11 Comparison of Mean Malaise Scores with Other Studies on Carers**

	Mean ( $\mu$ )	n
This study (Carers of older people)	6.72	150
Nolan and Grant (1989) (Carers in general)	8.97	554
Quine and Charnley (1987) (Carers of older people)	3.86	226
Quine and Pahl (1985) (Carers of children with learning disabilities)	5.83	200

Table 7.11 demonstrates that the mean malaise score for this study (6.72) is less than that for the Nolan and Grant (1989) study looking at carers in general ( $\mu=8.97$ ). One explanation for this finding may be the methodology employed by the researchers. As stated in Chapter 4 (section 4.2.2), their data were gathered through the inclusion of a questionnaire with a Carers National Association newsletter. It is possible that it was mainly carers who felt stressed who were motivated to complete and return the questionnaire. Thus, the research would result in a higher mean malaise score.

The data in Table 7.11 also show that the mean malaise score in this research was more than for the Quine and Charnley (1987) study researching carers of older people ( $\mu=6.72$  as

opposed to  $\mu=3.86$ ). In fact, in the latter study, carers were not deemed to be stressed (the cut-off point is lower than 5). One explanation for the difference in mean malaise scores in the two studies may be as proposed in Chapter 4 (section 4.2.2): namely, that over three-quarters (77%) of the carers in Quine and Charnley's (1987) research were caring for older people in receipt of social service provision, possibly contributing to a lower mean malaise score. It is not clear which services were received by these older people and therefore a direct comparison with services received by the cared-for older people in this study is not possible. However, in the present research just over one third of the carers ( $n=54$ , 36%) reported visits of at least once a month to the older person by a social worker and/or home-help and/or meals-on-wheels (see Q.27, Appendix 1). Hence, a lack of social support from formal sources may help to explain this difference in the mean malaise score.

The final study to be used for comparison of mean malaise scores is the Quine and Pahl (1985) study on carers of children with learning disabilities. The mean malaise score for the latter study is a little lower than the mean malaise score for this study ( $\mu=5.83$  and  $\mu=6.72$  respectively). One explanation for this slight difference in the mean malaise scores in the two studies could be that these children are a specialised group who, because of their particular disability, are known to health and social services and are therefore more likely to receive support from formal sources. However, carers of older people, in particular those from minority ethnic groups, are more isolated (McCalman, 1990), and therefore often unknown to service providers.

On the whole, the findings generated by this research are comparable to the carers in the above studies, in that two out of three of them exhibit stress levels of 5 and above. One additional explanation for the variations in mean malaise scores could be to the specific nature of this research, namely the focus on the separate cultural groups in this project. The

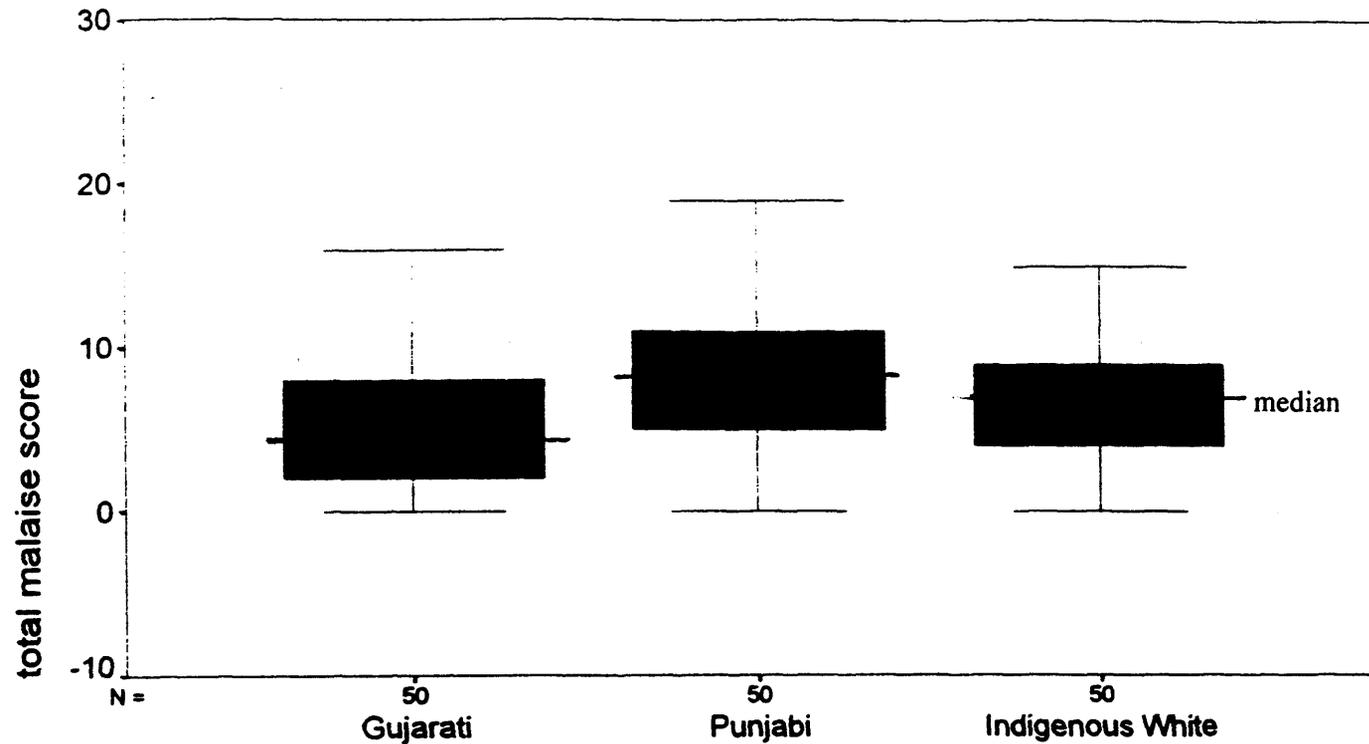
literature suggests that Asian older people and their carers are invisible firstly, because they have been regarded as numerically insignificant and, secondly, because the Asian community is seen 'to take care of its own' (Baxter, 1988; Patel, 1994; and see Chapter 3, section 3.5.1). Hence, disadvantages accompanying ethnicity may magnify the experience of caring and therefore influence perceived stress levels. The following section will examine any differences between the cultural groups in more detail.

### **7.5.1 Malaise Scores in the Three Cultural Groups**

Malaise scores can range from no score (0) to a maximum of 24. In line with other studies the data were dichotomised into one category not indicative of stress (scores 0-4) and another category that indicated the experience of stress (scores 5-24). It is therefore, firstly, important to explore the range of malaise scores reported by the three cultural groups. Secondly, it is interesting to discover how many carers in each group reported feeling stressed. Examination of the data showed that white indigenous carers reported the highest range of malaise items (0-20). In this group two thirds of carers scored a malaise of 5 and above (n=33, 66%). The range of scores was similar for the Punjabi carers (0-19), but here over three quarters of carers were deemed to experience stress (n=39, 78%). Gujarati carers' scores ranged from 0-16. Only half of the Gujarati carers scored a malaise of 5 and above (n=25, 50%). This information taken as a whole shows that almost two thirds of the sample were stressed (n=97, 65%). It now becomes interesting to look at the malaise scores in more detail.

A preliminary exploration of the data showed that the malaise scores were not normally distributed. To address this non-normality, non-parametric statistical tests were used to look for differences between the three cultural groups, and a box plot was generated (Figure 7.2).

**Figure 7.2 Median Malaise Scores For the Three Cultural Groups**



### definition of ethnicity

This figure exhibits the median malaise scores for the Gujarati, Punjabi and white indigenous groups (4.5, 8.5 and 7 respectively). Given the information on the malaise scores above, it is clear that the Punjabi carers reported the highest level of stress, followed by the white indigenous sample of carers, whereas the Gujarati group as a whole were not stressed (the median of 4.5 is below the cut-off point of 5 on the Malaise Inventory). In order to see whether or not there is a significant difference in median stress levels between the three groups, a one-way analysis of variance was carried out on the ranked data. This test addressed the issue of the non-normality of the data and, using the post-hoc test, had the added advantage of locating where the difference lay between the three groups. The one-way analysis of variance on the ranked malaise scores for the three cultural groups revealed a significant difference between the three different groups ( $F=5.17, p<0.007$ ).

In order to determine where the difference lay between the three groups, the Duncan's Multiple Range test revealed a significant difference between the Gujarati and Punjabi carers at the 5% level. This constitutes a key finding, in that the difference did not lie between either of the minority ethnic carer groups and the white indigenous sample of carers. Instead, there was a significant difference in the level and experience of stress between the Gujarati and Punjabi groups with Punjabi carers reporting a significantly higher level of stress. Further examination of the data revealed that the difference in the level of stress lay with the female carer groups. Here, over twice as many female Gujarati (n=19, 47%) as female Punjabi carers (n=7, 18%) were found not to experience stress (scores below the cut-off point of 5 on the Malaise Inventory), whereas considerably more female Punjabi carers than Gujarati carers reported stress (n=32, 82%; n=21, 52% respectively). A chi-square test employed on the data revealed a significant association between reported stress and the Punjabi and Gujarati female carer groups (see Table 7.12).

**Table 7.12 Malaise Scores in Gujarati and Punjabi Female Carers**

Malaise scores	Gujarati	Punjabi	Total
Not stressed (0-4)	19 (47%)	7 (18%)	26 (33%)
Stressed (5-24)	21 (52%)	32 (82%)	53 (67%)
Base	40 (99%)	39 (100%)	79 (100%)

chi-square=7.81, df=1, p<0.006

This is a revealing finding which necessitates a look for some possible explanations. It has already been established that the Gujarati group as a whole (of which the majority were female n=40, 80%) were less heavily involved in caring than were the Punjabi group of carers (of which the majority were also female n=39, 78%). A chi-square test of association shows that the level of care is related to the carers' experience of stress (see Table 7.13).

### 7.13 Malaise Scores by the Level <sup>12</sup> of Support Given by Carers

Malaise scores	Low	Medium	High	Total
Not stressed (0-4)	8 (53%)	31 (49%)	14 (19%)	53 (35%)
Stressed (5-24)	7 (47%)	32 (51%)	58 (81%)	97 (65%)
Base	15 (100%)	63 (100%)	72 (100%)	150 (100%)

chi-square=15.39, df=2, p<0.001

Table 7.13 demonstrates that there is no real difference in the numbers feeling stressed or not when providing a low level or a medium level of support (n=7, 47%; n=8, 53% and n=32, 51%; n=31, 49% respectively). However, four times as many carers objectively rate feeling stressed as opposed to not feeling stressed when providing a high level of support (n=58, 81%; n=14, 19% respectively). This finding echoes other research, which has found that older people requiring a higher level of support tend to have a carer malaise score of more than 5 (Quine and Charnley, 1987). It can be assumed that carers providing a high level of support to older people would also need to spend many hours providing this support, which has been found to increase carer burden (Stoller and Pugliesi, 1989). Exploration of the data in the present study showed that time spent on caring was indeed linked to providing a high level of support. In addition, almost one-third of carers who were stressed (n=29, 30%, of which the great majority were female n=25, 86%), reported that time spent on caring was the reason for feeling stressed (see Q.22, Appendix 1). Not surprisingly, out of the female carers, the largest group who reported this were Punjabi carers (n=12, 48%), followed by white indigenous carers (n=8, 32%), and Gujarati carers (n=5, 20%). This factor alone may help to explain the difference in the experience of stress in carer groups, and particularly between female Gujarati and Punjabi carers. Nonetheless, past research has shown that the most potent stressors may not be the objective features

<sup>12</sup> Low, medium and high refer to the levels of support given.

associated with events or circumstances, such as the level of care provided. Rather, it is a complex interaction of factors that predispose carers to stress. Nevertheless, Nolan *et al.* (1990) highlight the importance of the carer's perceptions of the demands associated with caregiving. It is therefore interesting to look at other explanations as to why some carers in this study should feel more stressed than others.

The literature shows that the locus of care is often with one person (Parker, 1990). This means that carers of older people often feel they carry the sole responsibility for the provision of care, even though many have other family around them and/or receive some form of help from formal sources (Harris, 1998). One crucial question, therefore, is to explore whether carers in this study also felt alone in this responsibility and whether this made them vulnerable to the experience of stress (see Q.59, Appendix 1). Hence, a chi-square test was employed to test the relationship between sole responsibility and stress (see Table 7.14).

**Table 7.14 Malaise Scores by Carers' Perception of Sole Responsibility**

Malaise scores	Not solely responsible	Solely responsible	Total
Not stressed (0-4)	40 (48%)	13 (20%)	53 (35%)
Stressed (5-24)	44 (52%)	53 (80%)	97 (65%)
Base	84 (100%)	66 (100%)	150 (100%)
chi-square=12.61, df=1, p<0.001			

Results revealed a significant association between feeling alone in the responsibility to care and reported stress. As can be seen, the distribution in terms of reported stress in carers who did not feel solely responsible for care of the older person was similar (n=40, 48%; n=44, 52% respectively). However, four times as many carers who did feel they carried sole

responsibility for care perceived stress as opposed to those carers who did not feel stressed (n=53, 80%; n=13, 20% respectively). In light of this result, it becomes pertinent to investigate whether there is any difference in the perception of feeling alone in providing care across the three cultural groups.

**Table 7.15 The Perception of Sole Responsibility for Care by Ethnicity**

Solely responsible	Gujarati	Punjabi	White	Total
Yes	13 (26%)	27 (54%)	26 (52%)	66 (44%)
No	37 (74%)	23 (46%)	24 (48%)	84 (56%)
Base	50 (100%)	50 (100%)	50 (100%)	150 (100%)
chi-square=9.90, df=2, p<0.008				

Table 7.15 shows there is a significant association between feeling alone in the responsibility to care and ethnicity: the majority of Punjabi and white indigenous carer groups did perceive sole responsibility to care for the older person (n=27, 54%; n=26, 52% respectively), whereas, almost three quarters of Gujaratis did not share this perception (n=37, 74%). This constitutes another interesting finding in that, yet again, there is a close congruence of scores in the Punjabi and white indigenous groups of carers. One explanation for this might be that the majority in both of these groups provided higher levels of care than did Gujarati carers (see Table 7.5). Clearly, the findings from this study indicate that the heavier the involvement of carers with an older person, the more they feel it is they who do all the actual caring. Hence, although it has been argued that subjective perceptions of individual circumstances are more important than the objective features of caring (Nolan *et al.*, 1990), at the same time it does appear in this study that how a situation is subjectively appraised depends on the level of care a carer needs to provide in the first place. As argued by Pearlin *et al.* (1990:588):

*'The relentless and progressively expanding demands of caregiving, together with ensuing secondary role strains, are capable of diminishing positive elements of self; this, in turn, leaves people increasingly vulnerable to stress outcomes'.*

This section on the perceived stress level in carers has demonstrated that the majority of carers in this study did feel stressed. Further exploration of the data revealed some significant differences between the three cultural groups, thus supporting hypothesis 2. The Gujarati sample as a whole was not stressed; however the white indigenous carers, and in particular Punjabi carers, exhibited quite high levels of stress. Given that the level of care provided by the different carer groups appears to have been an influencing factor in this outcome, it is relevant to explore some of the different aspects of care related to the level of care provision.

#### **7.6 The Sources and Nature of Stress**

The fact that stress was experienced by all three groups of carers has been made evident (see section 7.5 above). Clearly, the sources and nature of stress will vary with individual carers. Much depends on their personal interpretation of the different aspects of care provision in which they are involved. In general the sources of stress can be classified into four main categories: personal/practical, behavioural, intrapersonal/interpersonal and social/cultural (see Chapter 4, section 4.2.2). These aspects of caring identified in this research were similar to those found in other studies (Richardson *et al.*, 1989; Parker, G., 1990; Atkinson and McHaffie, 1992). Nonetheless, this study is unique in that it investigates how the caring role affects the three cultural groups and their experience of stress by looking for similarities as well as differences between the carer samples.

The provision of care involves different aspects of support; therefore this section has been divided into subsections concerning personal care (section 7.6.1), physical help (section

7.6.2), practical help (section 7.6.3), behavioural aspects of care (7.6.4), intra/interpersonal determinants (section 7.6.5) and social/cultural aspects of care (section 7.6.6)

### 7.6.1 The Provision of Personal Care

The literature defines two features of personal care, which may have a bearing on the difficulties experienced by carers (Twigg and Atkin, 1994). The first is that personal care may not only involve a large time commitment, but may also have to be performed at particular times or on demand as the need arises. The second is that this type of care involves touching and nakedness. In the present study, just over a half of all carers (n=78, 52%) reported that they provided regular help with tasks such as dressing, bathing, washing, shaving, using the toilet and incontinence care (see Q.8, Appendix 1). Personal care was largely given to older people requiring care for more than ten hours a day (n=44, 56%) and the majority were co-resident (n=58, 74%-see Table 6.14). Not surprisingly, the largest group requiring personal care consisted of the co-resident spouse/partner of the carer (n=29, 37%) who were also the largest group requiring a high level of care (n=21, 29%). Many spouse carers reported that they provided substantial help to their partner. As expressed by one carer:

*I have to do literally everything for him. I have to wash him, feed him, turn him, sort his catheter out and clean him up. When I say everything, believe me I mean absolutely everything.*

(white indigenous spouse)

In some cases, non-spouse carers were also heavily involved in personal care activities.

Sometimes this meant the need to care at night as well:

*I am changing her throughout the night. Sometimes twice a night and also sometimes very early in the morning about 3am. to 5am.*

(female Punjabi carer of her mother-in-law)

The provision of personal care was not always associated with caring for a family member. Four female carers looking after a female friend or neighbour helped with aspects of personal care, although this did not involve intimate care activities (it is not clear whether these friends/neighbours actually required or would have wanted more intimate personal care). Here, carers performed tasks such as hair care, doing up buttons etc. Clearly, in this study, the relationship of the carer to the older person appears to have been an important factor in the provision of more intimate personal care. As found by studies on caregiving, the taboos of personal caregiving can be a problem in caring relationships (Ungerson, 1987) and especially for Asian carers (George, 1993). Therefore, the provision of personal care across gender boundaries was understandably seen to be a problem to some of the carers in this study. As related by a female Punjabi caring for her father-in-law:

*It is very difficult to care for my father-in-law because of cultural reason. In our country women play very little part in looking after men. It is the duty of daughter-in-law to cook and clean for their elderly in-laws, but to give personal care is very difficult.*

This problem of crossing gender boundaries does appear to affect male carers even more. Indeed, none of the male carers in this study gave any personal care to a female other than his wife. This reflects the fact that, in caring, intimate bodily contact is more constrained for men than it is for women (Twigg and Atkin, 1994). Nonetheless, as found in other work on spouse carers, giving intimate personal care to a spouse/partner may still cause some angst for female carers (e.g., Parker, 1993). One example of this, found in the present study, was that even though one Punjabi carer was the wife, it still caused her considerable problems, in that she found providing this type of care both embarrassing and difficult. Not only can the provision of intimate personal care be embarrassing for both the carer and the older person receiving such care, it can also be perceived as distasteful and damaging to the relationship. For example, one white indigenous female who needed to deal with her husband's

incontinence reported that she found it so abhorrent that she no longer felt married to him. She really did not expect to have to provide incontinence care for her husband in later life. This also reflects the fact that different relationships imply different expectations of what is acceptable within the caring dyad. Ungerson (1987) found that a close emotional relationship based on a long history together might be a source of difficulty and obstruction for providing personal care to an older person. One carer who did not provide personal care to her mother reported that her mother simply would not allow it. Again, it is not clear from this study whether carers did not provide personal care because they felt it would be wrong to do so, or because the older person refused to allow such care, or whether personal care was not required.

Examination of the interview schedules revealed that both cross-gender and cultural barriers in the provision of personal care appeared to affect Gujarati and Punjabi carers. In order to investigate this further, an exploration of the data from the three cultural groups who gave personal care revealed that exactly one half of those providing this care were the white indigenous carers (n=39, 50%), whereas only about a quarter of Gujarati and Punjabi carers (n=20, 26%; n=19, 24% respectively) were involved in the provision of personal care. Given this apparent difference between the cultural groups, a chi-square test was applied to investigate the relationship between the cultural groups and the provision of personal care.

**Table 7.16 The Provision of Personal Care by Ethnicity**

Personal care given	Gujarati	Punjabi	White	Total
Yes	20 (40%)	19 (38%)	39 (78%)	78 (52%)
No	30 (60%)	31 (62%)	11 (22%)	72 (48%)
Base	50 (100%)	50 (100%)	50 (100%)	150 (100%)

chi-square=20.35, df=2, p<0.001

Table 7.16 reveals that there is a highly significant association between the giving of personal care and ethnicity. Clearly, the difference lies between the Asian groups of carers and the white indigenous sample, as more white indigenous than Asian carers provided personal care. Further exploration of personal care and the relationship of the carer to the older person by ethnicity was not possible due to small numbers. Nonetheless, one explanation for significantly fewer Asian than white indigenous carers providing personal care might be either that many of the Gujarati and Punjabi older people being cared for did not require personal care, or that intimate personal care provision to older people in Asian families, especially in terms of cross-gender boundaries other than one's spouse, is largely considered taboo (e.g. Ahmad, 1996).

This section has shown how the giving of personal care may be stressful to some carers. Further investigation of the data in terms of whether the provision of such care was associated with stress showed that over a third of carers who provided personal care also felt stressed, but this was not statistically significant ( $n=56$ , 37%;  $\chi^2=3.61$ ,  $df=1$ ,  $p>0.05$ ). Another possible primary stressor concerns the physical help given by carers.

### **7.6.2 The Provision of Physical Help**

In addition to the provision of personal care, carers also carried out a variety of physical tasks, which is another defining feature of caregiving (Twigg and Atkin, 1994). Physical help mainly included assisting the older person with walking, getting in and out of bed, going up and down stairs (where mobility allowed), getting in and out of chairs/wheelchairs, and feeding (see Q.8, Appendix 1). Given that carers experience a higher level of physical exertion than the general population (Parker, G., 1990; and see Chapter 4, section 4.2.3), it is pertinent to investigate whether the carers in the present study perceived the provision of physical care as stressful. Table 7.17 exhibits this information.

**Table 7.17 The Provision of Physical Care by Perceived Stress**

Physical care given	Not stressed (0-4)	Stressed (5-24)	Total
Yes	28 (53%)	73 (75%)	101 (67%)
No	25 (47%)	24 (25%)	49 (33%)
Base	53 (100%)	97 (100%)	150 (100%)

chi-square=7.84, df=1, p<0.006

The table demonstrates that over two thirds of all carers reported that they were involved in the giving of physical help (n=101, 67%). It also shows that there is a significant association between the provision of physical care and perceived stress. The source of this difference clearly lies with the fact that, although similar numbers of carers did not perceive stress whether they gave physical care or not (n=28, 53%; n=25, 47% respectively), three quarters of the sample who gave physical help did perceive stress (n=73, 75%). Therefore, in this research there is a clear link between the giving of physical help and perceived stress. Naturally, this finding has implications for service providers looking to design care packages to help carers.

Physical care was significantly more likely to be given to older people who co-resided with their carer (n=74, 73%-see Table 6.14 for chi-square result). Concerning those carers who provided physical care and those who did not, there were some differences between the Gujarati, Punjabi and white indigenous groups (n= 27, 54%; n=35, 70%; n=39, 78% respectively). A chi-square test of association was employed to investigate the relationship between the provision of physical care and ethnicity (see Table 7.18).

**Table 7.18 The Provision of Physical Care by Ethnicity**

Physical care given	Gujarati	Punjabi	White	Total
Yes	27 (54%)	35 (70%)	39 (78%)	101 (67%)
No	23 (46%)	15 (30%)	11 (22%)	49 (33%)
Base	50 (100%)	50 (100%)	50 (100%)	150 (100%)

chi-square=6.79, df=2, p<0.04

The results show a significant relationship between the provision of physical care and ethnicity. Although the majority in each group of carers gave physical help to the older person, over three quarters of white indigenous and almost three quarters of Punjabi carers, as opposed to just over one half of Gujarati carers, helped with this task. One possible explanation for this finding may be that significantly more Punjabi and white indigenous carers than Gujarati carers gave a higher level of care, of which physical care may be a main component.

Over a quarter of all carers (n=45, 30%- of which there were Gujarati n=12, 27%; Punjabi n=15, 33%; white indigenous n=18, 40%) were limited in what they could physically do for the older person. Not surprisingly, many of these were older people themselves (n=19, 43% aged 56 years and above), although five female Gujarati (11%) and five female Punjabi carers (11%), as opposed to one white indigenous female (2%), were aged between 26-40 years. Limitations in giving physical help were due to the fact that many carers were experiencing ill health themselves (n=18, 41%), and others were suffering from back problems and/or were unable to lift or move the older person (n=27, 61%). As expressed by one carer:

*If he falls I can't pick him up. I have to try and get help from the neighbours. Mind you, they don't like me getting them up late at night. He doesn't like me to either, but what else can I do.*

(female white indigenous carer of her husband)

This particular carer related that she herself felt inadequate when she could not help her husband, and he felt a fool when he fell over and hated the fact that his wife needed to get help in emergencies. Not surprisingly, such situations were upsetting for both of them. This source of stress was one that could have been mediated by the provision of an appropriate lifting aid. Indeed, one complaint common to all three groups of carers was the lack of available aids and equipment to allow them to care more efficiently. Exploration of the data revealed that almost one third of the carers (n=30, 30%) who provided physical care felt that they did not have sufficient aids and equipment to care (see Q.35, Appendix 1). These carers reported that basic equipment such as wheelchairs, eating aids, commodes and lifting equipment were apparently in short supply with a waiting list for some of the items. Carers also reported delays with equipment that needed installation. As related by one carer aged over 70 years:

*I was waiting for them to come and put in handrails to help her up the steps. The handrails arrived, I kept phoning and they said 'yes someone is down to do it'. In the end I had to do it meself. I was a bit worried, but they seem to be holding up all right.*

(male white indigenous carer of his wife)

Clearly, the lack of sufficient aids and equipment, which could help carers with the physical aspects of caring, means that carers are unnecessarily exposed to greater amounts and difficulty of work, thereby increasing the potential for stress.

This section has demonstrated that, as with the provision of personal care, there are some differences in the giving of physical help between the three cultural groups, which may be stressful to some carers. The provision of practical care, another possible primary stressor, is the next aspect to be explored.

### 7.6.3 The Provision of Practical Help

Almost all carers provided some form of practical help (n=147, 98%); this can, therefore, be considered a universal caring task rather than one which is culture specific. Practical help mainly consisted of assisting with or taking over necessary paperwork, dealing with financial matters, preparing meals, shopping, laundry, housework, gardening and giving medicines. In addition carers kept the older person company, took the older person to the hospital, doctor, community centre or day care, or church/temple and were involved in social visits (see Q.8, Appendix 1). Although almost all male carers and almost all female carers gave practical help, some gender differences were noted. As might be expected, most of the female carers helped with shopping, cooking, laundry and general housework. As related by one female carer:

*It's me who looks after Mum. I do her shopping, cleaning, fetch her pension, take cooked meals to her, everything like that.*

(female white indigenous carer)

All male carers (n=29, 100%), however, took the older person out, possibly because they had more access to private transport. Typical examples of this were:

*Yes, I take my father to the gurdwara, bring him to my house where he eats with us, and take him to the hospital and where he wants to go.*

(male Punjabi carer)

Overall, no particular problems were reported in the actual provision of practical care, except for that of providing help with, or taking full responsibility for, medication (n=96, 64% provided this care). Given that this type of care is normally associated with professional health care workers (Sadler, 1990), a chi-square test of association was carried out on the dichotomised stress data to determine whether the carers in the present research found giving this type of help stressful.

**Table 7.19 The Provision of Medical Help by Perceived Stress**

Medical help given	Not stressed (0-4)	Stressed (5-24)	Total
Yes	21 (40%)	75 (77%)	96 (64%)
No	32 (60%)	22 (23%)	54 (36%)
Base	53 (100%)	97 (100%)	150 (100%)

chi-square=21.14, df=1, p=0.000

The table shows that there is a significant association between the giving of medical help and perceived stress. Almost two thirds of carers who did not give medical help to the older person also did not perceive stress (n=32, 60%). Conversely over three quarters of carers providing medical help also perceived stress (n=75, 77%). It may be that the condition of the older person necessitating medical care was the real source of stress rather than the need to provide medical help. Nevertheless, this result has clear implications for health and social care providers if they wish to make practical help to carers a high priority. Interventions need to be in place to reduce the experience of stress either because of the illness/disability of the older person, or carers taking on the responsibility for the provision of medical help.

There were no real cultural differences in the number of Gujarati, Punjabi and white indigenous carers who provided this kind of help (n=29, 30%; n=37, 38%; n=30, 31%

respectively). For carers in all cultural groups this could involve dealing with specialised medical equipment such as oxygen bottles and nebulisers as well as the giving of injections and drugs.

The significant finding on giving medical help and stress accords with other work on caring, which has found that for some carers the responsibility was quite daunting (Twigg and Atkin, 1994). One such example in the present research is in the case of diabetes, where there is a need to ensure the correct balance of diet to the amount of insulin required. Being able to obtain the right foods, particularly for an Indian vegetarian diabetic diet, was occasionally a problem for the Gujarati and Punjabi speaking carers. One female Gujarati carer looking after her mother reported:

*We were told about the diabetic diet, but it was for a 'white' diet. We had to go to Leicester to find out about an Asian diabetic diet.*

This particular carer also reported that the nurse had showed her only once how to give the necessary injections. Neither she nor her mother was entirely satisfied with the amount of instruction given with such a potentially serious illness. One other area of practical care raised as a concern was that involving role reversal, particularly between spouses. As reported in other research (Zarit *et al.*, 1986), it was the added domestic duties previously carried out by the wife now requiring care that was more problematic for male carers. Again, in this research, no real cultural differences were apparent:

*There are too many things to do at once. I can't finish one job at a time. I've also had to learn to be a housewife. I don't like having to cook. Mind, you, I now appreciate what my wife has had to do all her life.*

(male white indigenous carer of his wife)

*My wife, she always cooked good food for me. Indian food takes a long time to cook. All the preparation of the different spices and vegetables. I also do the cleaning of the house, but my daughter, she comes to help me. She knows I find it difficult to do everything.*

(male Punjabi carer of his wife)

*All I do is look after my wife and do housework. My wife always did everything her way, very clean. I manage, but she would do better, more clean. I no longer have time for other things. Very hard.*

(male Gujarati carer )

For these carers it was clearly the amount and nature of tasks needed in order to provide care which was problematic and which were a source of stress (Pearlin *et al.*, 1990). This also accords with previous literature on practical aspects of care (see Chapter 4, section 4.2.3). For female carers the difficulty lay more with domestic duties previously carried out by the husband:

*My husband looked after money side. Now I must do. I ask son to help me. He understands what I must do.*

(female Punjabi carer of her husband)

*He used to deal with all the paperwork. I hadn't got a clue, but I've had to learn the hard way. He hates the fact that I do it instead of him. Not just that, he hates me having to do the garden. I don't mind that so much, it's just the way he looks at me.*

(female white indigenous carer caring for her husband)

*I find it difficult to do the garden and keep it looking nice. Before he had a stroke, he used to do all the gardening.*

(female Gujarati carer of her husband)

As the above discussion shows, some aspects of providing practical care can cause similar problems for all cultural groups. It appears that previous experience in carrying out the

different tasks tends to make the practical side of providing care much easier. Some main similarities and differences in the provision of personal, physical and practical care that have affected the three groups of carers in this research have been demonstrated. One final task-related primary stressor to be explored concerns supervision and the behavioural aspects of care.

#### 7.6.4 Supervision and Behavioural Aspects of Care

Although the physical tasks described above are relevant aspects in carers' experience of stress, they are not necessarily the only feature of caring (Twigg *et al.*, 1991). Supervision can, of course, include just watching over someone during meal times, or whilst the older person is cooking etc. Hence, for carers this particular aspect of task related care was largely a case of keeping an eye on the older person. The majority of carers (n=140, 93%) performed this task either in the same household (n=96, 69%) or elsewhere (n=44, 31%), which could be in the older person's own home or in warden controlled accommodation. Carers in all cultural groups expressed that they mainly needed to be around in case anything went wrong:

*I can't leave mother for long. I wait for my children to come home to have a shower.*  
(female Gujarati carer)

*Mother is very stubborn. She won't wait for anything. If I'm not there, she gets out of her chair and falls. My husband, he says it's my fault.*  
(female Punjabi carer of her mother-in-law)

*I only live down the road and I seem to spend more time with him. He's not safe, you know. He wanders about and doesn't know what he's doing. I worry about him at night when I'm not there.*  
(female white indigenous carer of her father)

Accordingly, supervision of the older person mainly included trying to ensure their safety. Examples of this included watching them make a cup of tea; listening out for them in the bathroom; making sure they had everything to hand, which they might need for a given period of time; and trying to make sure they didn't wander about or 'overdo it'. In some situations, supervision of the older person also included the safety of the neighbours. Carers, particularly white indigenous carers, expressed worries about the possibility that the older person might leave the gas on, leave an open unprotected fire at night, or smoke etc. All these were reported to be a possible risk, for which the carers felt responsible. One female white indigenous carer related that she had been verbally abused by her mother's neighbour both in person and by telephone. The reason for this was her mother's 'dangerous and aberrant' behaviour (the mother was diagnosed as suffering from Alzheimer's disease, see Chapter 4, section 4.2.4) and because she had not removed her to a home. Nevertheless, as this carer explained:

*I would be doing Mum a great wrong if I put her in a home. I would take away her independence, which she wants to hold on to. She doesn't want to come and live with me and she wants to stay in the home she has enjoyed all these years. It is a worry though.*

For this carer, her mother's well-being in the community would now not only include fears regarding her safety, but also concerns of how her mother would be treated by those living in her neighbourhood. In addition, this carer reported that she did not know how much longer she could stand by her mother's wish to maintain her independence. The feelings expressed by this carer and her mother in receipt of her care raise an important point. In the process of supervision, carers effectively assume control over the older person. This means that by the actual provision of care the personal freedom and independence valued by older people is eroded (Buchanan and Middleton, 1994). This dilemma in the need to supervise was also experienced by other carers (n=12, 8%, the majority of whom were female white

indigenous carers). These carers reported that the older person sometimes felt they were interfering or trying to run their lives for them:

*Mum accuses me of doing too much. She says I'm interfering, I'm a nag-bag. She tells me to go away and leave her to it, but she has already been in hospital with a broken leg. I just don't know what to do for the best.*

(female white indigenous carer of her mother)

On the other hand, the reverse appeared to be problematic for Asian carers, particularly female Punjabi carers of their mother-in-law:

*Mother-in-law is never happy. This I do wrong, that I do wrong. I can't do right. I do more and more to please her. My husband say nothing. Mother-in-law always right. I am beginning to hate her. My husband should think of me.*

*I have to be there all of the time. She expects me to. I can't go out without her. She could go to her other son in Leicester for a while, but she won't. My husband knows I feel pressure, but elders decide and I cannot speak. She is very demanding.*

These examples indicate that supervision can also be related to the behaviour of the older person and can involve some conflict and imbalance between carers and the older people they care for (Lewis and Meredith, 1988). On the one hand, carers may try their utmost to ensure that the older person they feel responsible for is properly being cared for by them, thereby perhaps denying them a certain independence and appearing overprotective. On the other hand, it appears that carers might be dominated or manipulated by the older person. Asian carers in this study, particularly female Punjabis caring for their mother-in-law, tended to report that they were seen as not doing enough. These findings accord with other work on social relationships among Asian communities in that 'conspicuous fulfilment of obligations' is expected (Ahmad and Atkin, 1996). This issue regarding the carer's response

to their role can overlap with secondary stressors such as intrapersonal/interpersonal aspects of caring and constitutes the next section to be explored.

### 7.6.5 Intrapersonal/Interpersonal Aspects of Caring

The main reason for carers assuming the caring role were explored earlier in section 7.2. In order to investigate intrapersonal aspects of care, carers were firstly asked whether they were prepared for the care they would need to provide (see Q.14, Appendix 1). Out of all carers, over three quarters (n=115, 77%) responded that they were prepared to give care. Typical comments by the carers which demonstrated this understanding, particularly regarding parents and parents-in-law, were:

*I know what it means to look after our elders. All our family has always done this. You know what to expect.*

(male Gujarati carer of his mother)

*It is normal in Indian families. When I was a child my mother looked after her mother-in-law. I look after mine.*

(female Punjabi carer)

As indicated, the cultural norms of Asian carers suggest that they are more prepared to care for non-spouse older people, which differed from the white indigenous sample:

*You know they're getting old, but you never really see yourself as having to look after them. It's almost as if you expect them to go on forever. The reality of course is different and it's quite a shock when you suddenly realise that the time has come.*

(female white indigenous carer of her father)

Given the above information, a chi-square test of association was used to investigate the relationship between being prepared for the care required to one's parents and parents-in-law and ethnicity (see Table 7.20).

**Table 7.20 Preparation for the Role of Caring for Parents/Parents-in-law by Ethnicity**

Prepared	Gujarati	Punjabi	White	Total
Yes	30 (86%)	35 (92%)	17 (63%)	82 (82%)
No	5 (14%)	3 (8%)	10 (37%)	18 (18%)
Base	35 (100%)	38 (100%)	27 (100%)	100 (100%)

chi-square=9.58, df=2, p<0.01

The result showed that there was indeed a highly significant association between being prepared to care for one's parents/parents-in-law and the three cultural groups. The difference here clearly lies mainly between the Gujarati and Punjabi groups on the one hand, and the white indigenous sample of carers on the other: fewer white indigenous carers appeared to be prepared for the care they would provide to the parent/parent-in-law. A possible explanation here may relate to cultural norms, such as expecting to care for a parent/parent-in-law, which may be a major determinant of preparedness for the caring role.

Evidence suggests that some carers feel less close to the person they care for since taking on the caring role (Sinclair, 1990; and see Chapter 4, section 4.2.5). Carers were therefore asked whether their relationship with the older person had changed in any way since they had assumed the caring role (see Q.23, Appendix 1). In this research, over one third of all carers (n=58, 39%) responded that in fact caring had brought them closer, particularly to their mother (n=18, 31%). There was no real difference in this feeling between the cultural groups:

*We're much closer now. I never really understood her before.*

(female white indigenous carer of her mother)

*Before my husband became ill we were ok., but now it is much happier between us.*

(female Punjabi carer)

*My father-in-law was always stern, now he needs my help he is a much kinder person.*

*I like him better.*

(female Gujarati carer)

The above quotations demonstrate how a deeper understanding of another person requiring help and support can bring about an increased closeness (Parker, 1993).

Only just over one tenth (n=18, 12%) perceived strain in the relationship since taking on the caring role. Again, there were no differences between the three cultural groups in this category. Strain was mostly felt when caring for mothers and mothers-in law (n=4, n=5 respectively) and caring for a spouse/partner (n=6). Previous research has shown that, where relationships had deteriorated in daughter/mother caring situations, this was often due to the daughter's perception of the mother's problematic behaviour (Lewis and Meredith, 1988). However, in spouse caring relationships, strain is felt more during the caring situation if they had a previously stormy relationship and/or as a direct response to the disability (Parker, 1993). Although, as pointed out above, the need to care can also bring people closer together (see section 7.2).

The remainder of the sample (n=74, 49%), either felt no change or had mixed feelings about their relationship with the older person. Parker's (1993) research on caring also found that carers learn to adapt to their situation. This would help to explain the observation that many carers did not perceive any change in their relationship. Thus, the findings from this study do not demonstrate that many carers feel that, in caring, their relationship with the cared-for person is negatively affected. Clearly, this is a positive finding and it is perhaps a factor that could be built upon in terms of understanding perceived stress.

Other secondary stressors that may be experienced by carers include social and cultural factors. The discussion of these will bring to a conclusion the possible sources of stress explored in this chapter.

#### **7.6.6 Social/Cultural Aspects of Caring**

One of the social factors that can affect carers' well-being is the financial aspect of care (see Chapter 2, section 2.4.3 and Chapter 4, section 4.2.1). In order to give care to the older person, particularly older parents, a few white indigenous carers (n=3) said they had purposely moved to a larger house in order to then look after their parent. The difference between the cultural groups here appears to be that, as found in other work, many older Asian people being cared for by their family were already co-resident before the need for care arose (Berthoud and Beishon, 1997). Some white indigenous carers (n=4) had extensions built on to their property in order to care; therefore financial involvement was an important consideration, although it is not clear whether these carers had totally funded this themselves. More carers from all cultural groups (n=25, 17%) had their homes upgraded (for example bathroom/toilet improvements for the disabled person) in order to provide better or easier care. As reported by the carers, these were often self-funded, although it appears that the carers thought it was money well spent and therefore did not regret the outlay. As demonstrated above (see section 7.6.2), some carers were not provided with basic aids and equipment, and this reinforces the fact that carers from all cultural groups may be forced to delve into their own or other family savings in order to provide care.

These findings accord with other work on the costs of informal care, which has shown that carers may finance housing adaptations/alterations, aids and equipment themselves in order to meet the specialised needs of the person requiring care (Glendinning, 1992). The items listed above are basically one-off costs and not required by all carers. However, many carers

incur extra household expenditure through increased heating, food, laundry, telephone, bedding, clothing, cleaning, repairs and transport costs (Glendinning, 1992). In this research, the most reported costs were for the telephone (n=36, 24%), travel (n=46, 31%) and laundry (n=31, 21%) and most of these were incurred by co-resident carers. On the whole, this is rather surprising, in that it could be expected that more carers would report extra costs through caring. In addition, no cultural differences were apparent. Research by Glendinning (1992) on 30 co-resident carers of mainly parents or parent-in law aged over sixty years, found that half the carers reported regularly using the telephone more, just over a half were regularly spending more on transport, and approximately three quarters of carers considered they had extra washing and drying.

Although most of the carers in the present study who reported these extra regular costs were also co-resident carers, they were also the majority who did not perceive any extra costs as a result of caring for an older person. Further examination of the data showed that the majority of those co-resident carers who did not think they were incurring regular increased expenditure were the Gujarati and Punjabi carers (n=28, 74%; n=37, 92% respectively). One explanation for this could be that, as mentioned above, many older Asian people were already co-resident before the need for care arose; therefore carers would not report extra costs through caring. These findings suggest that, especially for Asian carers, the regular financial costs of caring may not necessarily be a particular source of stress.

Other social factors (see Chapter 4, section 4.2.1), such as the presence of necessary equipment in order to provide care, may also impinge on carers' daily lives. During the course of the interviews it was noted that a few carers, mostly white indigenous (n=7), had beds, commodes etc. installed in their downstairs sitting/dining room. Some of these carers reported that not only was the equipment sometimes in the way, it also 'put people off' from

visiting them. Other white indigenous carers reported that they were unable to entertain socially without the constant presence of the older person for whom they were caring. As found in other research on carers of older people, reduced ability to receive guests owing to a lack of privacy had a detrimental effect on their social life (Jones and Peters, 1992). As the quotation below demonstrates, at times having the older person around all the time was fraught with difficulties and embarrassment for the carer:

*When I've got friends around for the evening, he decides he wants to go to bed there and then. He deliberately makes a fuss or makes rude noises until I do what he wants. He acts like a child really. Then there are the smells and the noises he makes when I'm trying to move him. It can, at times, be so off-putting. Only really good friends who understand make the effort to see me and stay for a while.*

(female white indigenous carer caring for her father-in-law)

This particular carer reported that, although she loved her father-in-law, his behaviour in front of others was beginning to 'get her down'. However, none of the Asian carers appeared to feel that the presence of the older person upset their ability to entertain. Instead, social factors impinged in a different way, such as a lack of freedom:

*I have no time for myself. No privacy. Father-in-law spends most of his time at home. He knows about everything I do, even a conversation on the phone.*

(female Punjabi carer)

This particular carer did not feel able to insist on some privacy for herself. She related that cultural norms meant that her life was not an individual life, but wholly part of the family (see Chapter 3, section 3.3.3).

This penultimate section of the chapter has demonstrated some of the social and cultural constraints impinging on the carers in this study. It has also indicated that the financial costs

of caring cannot be easily quantified and that, through caring, carers may find themselves socially isolated and/or lose a sense of personal freedom.

The possible sources and nature of stress for carers, as indicated by the literature and the carers researched, has shown that, although individual circumstances vary, many similarities as well as differences between the three cultural groups can be discerned.

### **7.7 Conclusion**

This chapter has explored the psychosocial impact of caring on informal carers of older people in three different cultural groups. It has enquired into informal carers' feelings of well-being by examining the levels of perceived morale and stress in the three groups of carers researched. It has also looked at different aspects of providing care to an older person that may affect the way carers feel about themselves and significant others as a part of their daily life.

The qualitative together with the quantitative evidence used throughout this chapter has shown how cultural distinctions can influence the nature of care given, its perception, and how the caring role has impacted on carers' feeling of well-being. Results showed that the motivation to care differed between the Gujarati and Punjabi and white indigenous carer groups, in that Gujarati and Punjabi carers reported to care more out of duty than love. Clearly, the language of caring differs in the South Asian communities, and is a domain which warrants further research.

Analyses showed that there was no significant difference between the three cultural groups and their perceived level of morale. However, there was a significant association between ethnicity and perceived emotional health, which was significantly associated with perceived

morale. Hence, a link between ethnicity, emotional health and morale has been suggested. The findings from this research lend support to hypothesis 2 regarding stress and the three groups of carers. Results revealed that the Punjabi sample reported a significantly higher level of stress than either the white indigenous, or particularly the Gujarati carer group.

One interesting finding, which provides explanations for the above results, was that the Punjabi group of carers provided the highest level of support to older people. Although perceptions of one's role are influential in how carers experience of stress, it is clear that the more caring responsibilities carers have, the less likely they are to report higher levels of perceived morale and the more likely they are to report the experience of stress. Given that the Gujarati group of carers gave a significantly lower level of support it was not surprising that this group also perceived higher levels of morale and lower levels of stress than either the Punjabi or white indigenous carer groups. Against this background, the following result chapter will now explore how carers might cope with their responsibilities of caring.

## **CHAPTER EIGHT**

### **CARERS' COPING MECHANISMS**

#### **8.1 Introduction**

This chapter examines and analyses the extent and manner in which the three cultural groups cope with their caring role as part of their daily lives. In common with Chapter Seven the chapter uses both quantitative and qualitative information to provide a vivid commentary in support of the findings. The analysis is focused on an examination of hypothesis 3 concerning coping levels and strategies that was put forward in Chapter Five. The purpose of the chapter is, therefore, to discern what coping factors can help to mediate the experience of stress and are available to the different cultural groups. It also probes into the differing unmet needs that are experienced by carers of all communities. The chapter builds the argument to the analytical conclusions of this thesis.

The chapter is divided into three main parts. The first section begins by looking at the overall perceived coping ability of the different carer groups (section 8.2.1). Following this, the internal coping mechanisms employed by the carers are examined (section 8.2.2). The chapter finally looks at the external coping strategies concerning the use of social support employed by the carers (section 8.3).

#### **8.2 Carers and Coping**

In the previous chapter it was established that the three cultural groups of carers in this study not only perceived a variation in levels of morale, but their experience of perceived stress was also significantly different. Given that coping abilities are the next psychosocial aspect of caring to be discussed, it is interesting at this point to examine the inter-relationship between morale, stress and coping as any explanation for one may account for explanations

in others. A Spearman's rho correlation matrix of the data on the carers' perceived morale (Cantril's Ladder, 1965), stress (The Malaise Inventory, Rutter *et al.*, 1970) and carers' coping abilities (see Q. 74, Appendix 1) is presented in Table 8.1.

**Table 8. 1 Correlation Matrix of Morale, Stress and Coping**

	Morale	Stress	Coping
Morale	1.000		
Stress	-0.4682*	1.000	
Coping	0.4009*	-0.4600*	1.000

\* (p=0.000)

The table demonstrates that, in this study, there is a significant correlation between perceived carer morale, stress and coping ability. Carers' perceived morale is positively correlated with perceived coping ability and negatively correlated with perceived stress. This indicates that the more a carer perceives they are coping, the better their morale. Conversely, higher perceived stress levels in carers are related to lower perceived morale and lower perceived coping abilities.

Given that past research has also shown that carers facing similar stressors, such as caring for an older person, are affected by them in dissimilar ways (Pearlin *et al.*, 1990), what now becomes important is to look at mediators to help provide an explanation for these differences. Hence, the carers' coping abilities, as well as their internal and external coping strategies are examined (see Chapter 4, sections 4.1 and 4.4). Due to the differing elements in coping, hypothesis 3 is subdivided into three parts.

**Hypothesis 3:**

*there will be a significant difference between the three groups in terms of a) perceived coping ability, b) internal coping methods and c) external coping strategies.*

This first section examines the extent to which the carers in this study perceived their ability to cope with their caring role by addressing part a) of hypothesis 3.

**8.2.1 Overall Perceived Coping Ability of Carers**

In order to ascertain whether the different cultural groups of carers perceived that they were coping with their caring role in conjunction with their everyday life, they were asked to respond to a five point rating scale, which was taken as a measure of their perceived coping ability. The five point rating scale of perceived coping ranged from not coping very well (1)<sup>12</sup> to coping very well (5), (see Q.74, Appendix 1); the responses of the different groups are shown in Table 8.2.

**Table 8.2 Perceived Coping Ability by Ethnicity**

Coping	Gujarati	Punjabi	White	Total
1 Not very well	1 (2%)	2 (4%)	2 (4%)	5 (3%)
2 Not well	1 (2%)	7 (14%)	0 (0%)	8 (5%)
3 Neither	13 (26%)	23 (46%)	12 (24%)	48 (32%)
4 Well	14 (28%)	12 (24%)	8 (16%)	34 (23%)
5 Very well	21 (42%)	6 (12%)	28 (56%)	55 (37%)
Base	50 (100%)	50 (100%)	50 (100%)	150 (100%)

Table 8.2 shows that from the entire sample over half of the carers (n=89, 59%) reported that they felt they coped 'well' or coped 'very well'. In terms of the three cultural groups

<sup>12</sup> Numbers in brackets correspond to the score on the five point rating scale.

almost three quarters of the Gujarati carers (n=35, 70%) and white indigenous carers (n=36, 72%) reported that they coped 'well' or 'very well', whereas only just over a third of Punjabi carers felt they coped 'well' or 'very well' (n=18, 36%). This finding can also be corroborated by some of the quotes made by different carers during the research. Typical comments by both Gujarati and white indigenous carers were:

*I feel I cope well with looking after my husband. You learn to adapt and balance the needs.*

(female Gujarati carer)

*I just get on with it. Mum knows I can only do so much, so we both know where we stand. If I couldn't cope I'd try and get help, but I can. It's fine.*

(female white indigenous carer)

The literature shows that coping has three possible functions. These are the control of a situation giving rise to stress; managing the meaning of the situation, thereby reducing the threat; and controlling the stress symptoms arising from the situation (Pearlin *et al.*, 1990). Hence, the qualitative evidence presented above demonstrates two of the three functions of coping used by carers. These are by, firstly, managing a stressful situation, for instance by adapting and balancing needs, and secondly, by managing the stress symptoms by only being prepared to do so much (see Chapter 4, section 4.4).

In addition to over a half of all carers expressing good coping abilities, almost a third (n=48, 32%) were uncertain about their perceived ability to cope and therefore registered their responses in the middle of the perceived coping continuum. Again, the three cultural groups were divided in a similar way with a close congruence in responses between the Gujarati and white indigenous carers (n=13, 26%; n=12, 24% respectively). The Punjabi group of carers stood out with almost half (n=23, 46%) reporting uncertain coping abilities.

Only a small number of all the carers (n=13, 9%) felt that they were definitely 'not coping well/very well'. Most of these were the Punjabi carers (n=9, 18%). The Gujarati and white carer groups thus reported a more positive outlook towards their caring role than the Punjabi group. Typical examples of this latter group's more negative perceived coping abilities were:

*It is hard. I don't like having to do some things. I have to do too much. I don't feel well. I do these things because I have to. I need more help.*

(female Punjabi carer of her father-in-law)

*No, I think I don't do so well. My mother is not good. It is all on me to do. I work in a factory on the machine. I go home, I work more. I go to bed, but I don't sleep well.*

(female Punjabi carer of her mother)

Clearly, the results and general comments so far show some discernible divisions between the three cultural groups of carers researched. In order to explore this further the data were dichotomised<sup>13</sup> into coping (points 4 and 5 of the rating scale) and not coping (points 1-3 of the rating scale). As the response of neither coping 'well' nor 'not well' indicated that these particular carers felt uncertain about their coping abilities, this category was classified with the overall view of 'not coping well'. A chi-square test of association was then employed to investigate the relationship between ethnicity and the dichotomised perceived coping ability. This revealed a significant relationship between ethnicity and perceived coping ability (chi-square=16.96, df=2, p<0.001). From an examination of Table 8.2, it is clear, that the responses from the Punjabi group of carers were more associated with uncertainty or a perceived inability to cope. The interesting question here was why the Punjabi carers researched should perceive less positive coping abilities. One factor which may have had a bearing on this finding was the fact that the great majority of Punjabi carers (n=31, 62%)

<sup>13</sup> The distribution of the scores did not allow for a three way division of the data.

provided a higher level of support to the older person (see Table 7.5). To establish whether there was any association between perceived coping ability in the three groups and the provision of high levels of support a chi-square test was carried out on the dichotomised coping variable by ethnicity controlling for those giving a high level of support to the older person. Table 8.3 details this information.

**Table 8.3 Perceived Coping Ability and Ethnicity by a High Level of Support**

Coping ability	Gujarati	Punjabi	White	Total
Coping	8 (57%)	10 (32%)	19 (70%)	37 (51%)
Not coping	6 (43%)	21 (68%)	8 (30%)	35 (49%)
Base	14 (100%)	31 (100%)	27 (100%)	72 (100%)

chi-square=8.62, df=2, p<0.02

Results show a significant relationship between perceived coping ability in those providing a high level of support and ethnicity. As can be seen, the majority of the Punjabi group of carers (n=21, 68%) who provided a high level of care perceived that they did not cope particularly well, whereas the Gujarati and white indigenous carers appeared to cope better despite providing a high level of support. Given that there was a similar proportion of Punjabi and white indigenous carers providing a high level of care (n=31, 62%; n=27, 54% respectively) a further chi-square test was carried out to test for a difference in coping abilities between these two groups. This showed that there was indeed a significant difference in the coping abilities of the Punjabi and white indigenous carer groups who provided a high level of care (chi-square=8.38, df=1, p<0.004). One explanation for this finding might be that more Punjabi carers than white indigenous carers co-resided and cared for 50 hours or more per week (see Table 6.17). Clearly the provision of higher levels of support would also require a larger time commitment to caregiving, and expose carers to a

number of both primary and secondary stressors (see Chapter 4, section 4.4). Secondary stressors include a doubt about one's competence (Aneshensel *et al.*, 1993); given that most Punjabi carers reported communication problems with formal service providers (see Table 6.5), this may also help to explain why Punjabi carers perceived more uncertain or negative coping abilities. Clearly, having to provide higher levels of care for many hours every week, yet being unable to communicate effectively with professionals who might be able to help, may result in a lesser perceived coping ability. This would also help to explain the previous findings of fewer Punjabi carers perceiving themselves as having higher levels of morale, and more Punjabis reporting a significantly higher level of perceived stress than the Gujarati and white indigenous carer groups (see Table 7.7, Figure 7.2).

The finding regarding carers' coping abilities thus supports part a) of hypothesis 3, in that the different cultural groups of carers perceive their coping abilities differently. This finding is now explored further by examining whether there are any differences in the type of internal coping mechanisms carers may use in their everyday lives.

### **8.2.2 Carers' Internal Coping Mechanisms**

This section explores carers' internal coping techniques, thereby addressing the second part (b) of hypothesis 3 outlined earlier. Most approaches to internal coping mechanisms make the distinction between active and avoidance coping mechanisms (Holahan and Moos, 1987). Active coping strategies include overt behaviour to deal with the challenge and cognitive efforts to manage the problem, whereas avoidance coping techniques are used to deny, minimise or simply ignore problems by withdrawing attention from the threat (Holahan and Moos, 1985).

Given that adaptation to stressful problems may depend upon the type of coping mechanism employed, the coping strategies used by the carers in this study were categorised as either

active or avoidance processes (adopted from determinants of coping suggested by Holahan and Moos, 1987; Barker *et al.*, 1990- see Chapter 5, section 5.6.2). During the interview, carers were asked to respond either 'yes' or 'no' to 10 main coping strategies (see Q.69, Appendix 1), which the carers might use in their caring role. Table 8.4 details how many of the carers in each cultural group reported using each of the coping strategies (items 1-5 consist of active coping strategies, items 6-10 are composed of avoidance coping mechanisms) and forms the basis for discussion of active and avoidance coping methods used by the carers in the study (see Chapter 4, section 4.4).

**Table 8. 4 Use of Active and Avoidance Coping Strategies by Ethnicity**

Coping strategies	Gujarati	Punjabi	White	Total
<b><u>ACTIVE</u></b>				
1. Overcoming of problems	24 (13%)	30 (15%)	43 (15%)	97 (14%)
2. Not worry	28 (16%)	25 (13%)	48 (16%)	101 (15%)
3. Be positive	27 (15%)	20 (10%)	44 (15%)	91 (14%)
4. Release emotions	27 (15%)	28 (14%)	35 (12%)	90 (13%)
5. Active planning	18 (10%)	6 (3%)	28 (10%)	52 (8%)
<b><u>AVOIDANCE</u></b>				
6. Ignore problems	11 (6%)	32 (16%)	20 (7%)	63 (9%)
7. Avoid problems by keeping busy	23 (13%)	31 (16%)	35 (12%)	89 (13%)
8. Eat/drink/smoke/ take pills more	9 (5%)	5 (3%)	20 (7%)	34 (5%)
9. Sleep more	3 (2%)	4 (2%)	1 (0.3%)	8 (0.1%)
10. Avoid people	10 (6%)	13 (7%)	17 (6%)	40 (6%)
Base	180 (100%)	194 (100%)	291 (100%)	665 (100%)

Table 8.4 shows that the carers in this study reported using active methods of coping (items 1-5; n=431, 65%) more than avoidance strategies (items 6-10; n=234, 35%). Overall, the carers therefore appeared to favour a method of coping considered more effective for psychological adjustment (Holahan and Moos, 1985 and see Chapter 4, section 4.4).

In terms of cultural differences, Table 8.4 shows that the white indigenous group reported using more of both active and avoidance mechanisms as a whole than either the Gujarati or Punjabi groups (n=291, 44%; n=180, 27%; n=194, 29% respectively). A chi-square test of association was applied to investigate the relationship between the use of active and avoidance coping techniques and ethnicity (see Table 8.5).

**Table 8.5 Number of Active and Avoidance Coping Strategies by Ethnicity**

Coping mechanisms	Gujarati	Punjabi	White	Total
Active	124 (69%)	109 (56%)	198 (68%)	431 (65%)
Avoidance	56 (31%)	85 (44%)	93 (32%)	234 (35%)
Base	180 (100%)	194 (100%)	291 (100%)	665 (100%)
chi-square=19.43, df=2, p<0.01				

A highly significant chi-square test indicated that there was an association between the coping mechanisms used and ethnicity. This confirmed that proportionately more active coping techniques were employed by Gujarati and white indigenous carers, than by Punjabi carers (n=124, 69%; n=198, 68%; n=109, 56% respectively). Conversely, relatively more avoidance coping strategies were used by the Punjabi carer group than by Gujarati and white indigenous carers (n=85, 44%; n=56, 31%, n=93, 32% respectively). This constitutes an interesting finding in that there is a close congruence in the proportions of active and avoidance coping mechanisms in the Gujarati and white indigenous carer groups, whereas one might have expected greater similarity between the Gujarati and Punjabi carers.

Past research has suggested that there may be differences in traditional Eastern and Western cultures (Shaw *et al.*, 1997). The former stresses family values and interpersonal harmony, while the latter encourages individualism and assertive action (see Chapter 3, sections 3.3.2 and 3.3.3). This suggests that coping strategies would also differ in that those from a Western culture would be more likely to use active coping styles and less likely to employ avoidance techniques than Asians (Shaw *et al.*, 1997). Unlike Shaw *et al.* (1997), who found no statistical significance in either active or avoidance coping by carers and the different cultural groups, this research has shown that there is a significant association between coping styles and ethnicity. Explanations for this might be that either different coping strategies are situational and change over time whilst caring long term. On the other hand it might be that a process of acculturation has taken place where primary beliefs and behaviours are modified and characteristic patterns and behaviours are absorbed from the mainstream culture (Aranda and Knight, 1997).

Clearly, the present research is unable to determine whether acculturation has taken place; nevertheless, the findings so far indicate that there is scope for further research in this area. Given that active coping may be considered a more positive approach than avoidance strategies, the two coping styles will now be discussed separately. The use of active coping mechanisms is discussed first.

#### **8.2.2.1 Carers' Use of Active Coping Strategies**

Table 8.5 demonstrated the number of active coping strategies used by the three cultural groups. White indigenous carers used the highest number of active coping methods (n=198, 46%), followed by the Gujarati group of carers (n=124, 29%) and the Punjabi carers (n=109, 25%). Table 8.6 lists the number of active coping methods used by the carers in each cultural group.

**Table 8.6 Number of Active Coping Strategies Used by Ethnicity**

Number of active coping strategies	Gujarati	Punjabi	White	Total
0	5 (10%)	9 (18%)	0	14 (9%)
1	12 (24%)	10 (20%)	0	22 (15%)
2	8 (16%)	10 (20%)	5 (10%)	23 (15%)
3	8 (16%)	7 (14%)	13 (26%)	28 (19%)
4	13 (26%)	12 (24%)	11 (22%)	36 (24%)
5	4 (8%)	2 (4%)	21 (42%)	27 (18%)
Base	50 (100%)	50 (100%)	50 (100%)	150 (100%)

In the white indigenous carer group, carers used a minimum of two active coping strategies and almost one half (n=21, 42%) used the full range of active coping mechanisms listed in Q.69. Ten percent (n=5) of Gujarati carers did not report using any of the active coping methods and only four (8%) used all five. In the Punjabi carer group nine carers (18%) reported using no active coping mechanisms and only two (4%) used the whole range of strategies listed. Clearly, more white indigenous carers than Gujaratis or Punjabis used a fuller range of active coping approaches. As detailed in Table 8.4, active coping strategies can include ways of overcoming problems, trying not to worry, being positive, releasing emotions and making a plan of action to follow. How the carers coped with their role was noted during the interviews. Typical examples of active coping strategies employed by the carers, which indicate some of the differences between the three cultural groups, were:

*I sometimes raise my voice a bit to drive the point home. Like when he won't take his pills. I tell him that unless he does he'll end up back in hospital. Most of the time he does see sense in the end.*

(female white indigenous carer of her father)

Here the carer is releasing her emotions by getting a little angry with the older person in her care. She related that on occasions she needed to be firm with her father, otherwise he would simply not listen to her. Carers also tried to see the positive side of things and thereby make some sense and meaning of the situation:

*I know he's ill, but I try to see good side of life. We have many years to be together and be with the family.*

(female Gujarati carer of her husband)

Trying not to worry was the active coping strategy used the most by the carers participating in this study (n=101, 67%):

*I am going to India for few weeks. I am going to see my family. The social worker has got a nurse to look after my wife when I'm in India. I must go, I won't worry about her now.*

(male Punjabi carer of his wife)

In a sense this carer, by arranging for a nurse to take care of his wife whilst he was away, also used an active planning strategy by making a plan and following it, although it is possible that he did not realise this himself. In fact, making a plan and following it was the least reported active coping strategy by all carers (n=52, 35%). From the number of carers in each cultural group who reported its use (see Table 8.4), it is clear that considerably more white indigenous than Gujaratis, and particularly more white than Punjabi carers, employed this strategy (n=28, 56%; n=18, 36%; n=6, 12% respectively). Thus, there does appear to be some difference in the understanding of active planning, and caution will need to be exercised when interpreting this particular coping strategy as communication problems, particularly in the Punjabi group (see Table 6.5), may have contributed to this finding. More general comments by carers who deliberately made a plan of action and followed it included:

*My life is so busy. I work full-time and I'm involved in a charity organisation. I've got a family and I look after Mum on top of it. I constantly make lists of things I've got to do and when I've got to do them. I plan everything ahead.*

(female white indigenous carer)

In a sense, the act of planning is linked to the final active coping strategy to be explored, namely that of thinking about ways of overcoming problems. To some extent one also needs to plan ahead in order to surmount a difficulty or anticipate one. In order to do this, seeking help and advice from both formal and informal sources (n=68, 70%) was reported as the strategy mostly used by the male (n=18, 62%) and female carers (n=50, 41%) in all three cultural groups:

*When there is a problem with mother-in-law, I ask my husband first what to do.*

(female Punjabi carer)

*A lot of my friends work in the social services. If I need advice, I usually ask them first. They tell me who to contact for help.*

(female Gujarati carer of her mother)

*The carer's centre in Kettering is brilliant. You can have a chat and find out anything you need to know.*

(female white indigenous carer of her husband)

All of the five active coping strategies discussed above were also examined in terms of reported use of each method and their employment by the three cultural groups. Chi-square tests on the data showed that there was a significant association between four out of five of the active coping strategies and ethnicity.

**Table 8.7 Active Coping Strategies Employed by Ethnicity**

Strategy No. <sup>14</sup>	Gujarati	Punjabi	White	chi-square	df	p
1	24	30	43	16.51	2	<0.001 * <sup>15</sup>
2	28	25	48	28.43	2	=0.000 *
3	27	20	44	25.53	2	=0.000 *
4	27	28	35	3.17	2	<0.205
5	18	6	28	21.43	2	<0.0001 *

Table 8.7 shows that there were significant associations between thinking of ways to overcome problems (strategy no.1), trying not to worry (strategy no. 2), trying to see the positive side of a situation (strategy no. 3), making a plan of action to follow (strategy no. 5) and the cultural groups. Not surprisingly the main difference for all these significant chi-square tests lies between the white indigenous and Asian carer groups, and in particular between the white indigenous and Punjabi carers. Possible contributory factors for these outcomes might be that, as Punjabis reported significantly more communication problems, they were less able to seek advice or help and therefore overcoming problems or making a plan of action to follow was more difficult. In addition, given that the Punjabi carers reported significantly more stress, generally lower levels of morale, and gave higher levels of care than the other two carer groups, it is possible that their feeling of self-esteem and mastery was negatively affected. Recent research has shown that 'loss of self' is significantly associated with frequency of care and overload (Noonan and Tennstedt, 1997). Clearly, a feeling of loss of personal control will affect coping strategies and means they are less likely to see the positive side of a difficult situation and more likely to worry.

<sup>14</sup> Coping strategy numbers used are the same as those in Table 8.4.

<sup>15</sup> \* denotes a significant finding.

In general, the data on active coping approaches by the carers accord with other work on coping. In the present research almost two thirds of all carers (n=97, 65%) reported that they thought about overcoming problems, and over two-thirds (n=101, 67%) said they tried not to worry (see Table 8.4). In a study by Barker *et al.* (1990), on 1040 adults in Britain, the same two methods (overcoming problems and trying not to worry) were also found to be the most favoured active cognitive coping strategies (88% and 85% respectively). Hence, it appears that these two coping mechanisms may reflect more stable aspects of coping in general life as well as in caregiving. Unfortunately, Barker *et al.* (1990) did not detail the ethnicity of participants and therefore any possible comparison in terms of cultural differences cannot be made.

#### **8.2.2.2 Carers' Use of Avoidance Coping Strategies**

Having looked at the active coping components used in this study, the thesis now focuses on the total number of avoidance coping mechanisms, which were detailed in Table 8.5. Of the avoidance techniques used, more were employed by the white indigenous and Punjabi carers than the Gujarati carers (n=93, 40%; n=85, 36%; n=56, 24% respectively). As shown in Table 8.4, avoidance coping mechanisms include ignoring problems, avoiding problems by keeping busy, eating/drinking/smoking/taking pills more, sleeping more and avoiding people.

Table 8.8 lists the frequency of avoidance coping methods used by the carers in each cultural group. It shows that none of the carer groups used more than four avoidance coping techniques. Hence, unlike the active coping strategies, none of the carers reported using the full range of possible techniques listed.

**Table 8.8 Number of Avoidance Coping Strategies Used by Ethnicity**

Number of avoidance strategies used	Gujarati	Punjabi	White	Total
0	19 (38%)	11 (22%)	8 (16%)	38 (25%)
1	13 (26%)	10 (20%)	13 (26%)	36 (24%)
2	13 (26%)	15 (30%)	12 (24%)	40 (27%)
3	3 (6%)	11 (22%)	12 (24%)	26 (17%)
4	2 (4%)	3 (6%)	5 (10%)	10 (7%)
Base	50 (100%)	50 (100%)	50 (100%)	150 (100%)

Over one third of Gujarati carers (n=19, 38%) did not use any of the avoidance coping methods and only two used four. Almost a quarter of Punjabi carers (n=11, 22%) did not report using avoidance strategies and only three used four. In the white indigenous carer group, only eight (16%) carers reported not using any avoidance coping techniques, and five carers reported employing only four. Therefore, the data indicates that not only did fewer Gujaratis employ avoidance mechanisms, they also used a lesser number of avoidance strategies than either the indigenous white or Punjabi carer groups.

The most used avoidance strategy by carers was to avert difficulties by keeping busy (n=89, 59%). As indicated in Chapter 5 (section 5.6.2), this particular coping strategy could have been classified as either active or avoidance (Barker *et al.*, 1990). Interestingly in Barker *et al.*'s (1990) study, it was categorised as active behaviour and was found to be one of the most popular overall methods of coping. Given the findings in the present study on carers, it is suggested that this particular coping mechanism, although active in nature, is perhaps more one of avoidance, especially for people in a caring role. Typical comments made by the carers in this study which demonstrate this were:

*Elsie<sup>16</sup> can be awkward at times. She can really upset me. When she's in a mood I keep out of her way for as long as I can, like doing a bit of gardening, but I know when I go back in I've still got to put up with her tantrums.*

(male white indigenous carer of his wife)

This particular carer related that he sometimes needed to put some space between himself and his wife. Going outside and away from his wife, but still being there to keep an eye on her, meant that he was able to cope, although he did not particularly like gardening. It also meant that the problem was still there to be dealt with. Although this particular carer used this strategy because of his wife's behaviour, other carers put off carrying out a physical task they found difficult to deal with:

*My husband has a catheter. I have to change the bag, but I hate having to do this. I tell him soon, soon, I'm too busy now.*

(female Gujarati carer)

The next most used avoidance technique by the carers in this study was that of ignoring problems (n=63, 42%). In Barker *et al.*'s (1990) study, this strategy was also found to be one of the most popular avoidance coping techniques (36%). As described by one of the carers, one example of this was:

*She always complains about something. I just let her say things and ignore it. She tells my husband when he comes home. I don't care anymore.*

(female Punjabi carer of her mother-in-law)

Whereas this carer found she could cope if she simply ignored her mother-in-law, other carers coped by avoiding the older person they were caring for, or others such as wider family members and outsiders:

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<sup>16</sup> The name has been changed to protect anonymity

*I don't answer the phone and I don't open the door when I don't want to talk to anybody. Especially if I think it is my mother. She just goes on and on.*

(female Gujarati carer of her mother)

*Sometimes I avoid my sister. She comes and tells me what I should be doing. She never takes Dad anywhere, but she's got the cheek to say 'If I were you I'd do this or that'. She gets on my nerves.*

(female white indigenous carer)

In addition to the above avoidance strategies employed by carers, a few reported they tended to sleep more (n=8, 3%):

*I stay in bed as long as I can and I go to bed as soon as I can.*

(female white indigenous carer of her mother)

White indigenous carers rather than Gujarati or Punjabi carers tended to eat/drink/smoke/take pills more (n=20, 40%; n=9, 18%; n=5, 10% respectively). As related by one white indigenous carer of her mother:

*Sometimes Mother is really too much for me to handle. She's getting worse. When I've been to see her, I'm all uptight. I get in and the first thing I do is pour a glass of wine and light a fag. By the end of the night I've probably finished the bottle and smoked the whole packet. It's costing me a fortune.*

(female white indigenous carer)

The fact that white indigenous carers, in particular, used the above coping strategy is not really that surprising given that smoking and drinking are perhaps more acceptable in Western societies. Conversely, smoking and drinking are not deemed an option to many in the Gujarati and Punjabi carer groups because of cultural and religious observance.

As with the active coping strategies, the above avoidance techniques were examined in terms of their reported use and their employment by the three cultural groups. Chi-square

tests of association showed there was a significant relationship with three of the five avoidance coping strategies and ethnicity.

**Table 8.9 Avoidance Coping Strategies Employed by Ethnicity**

Strategy No. <sup>17</sup>	Gujarati	Punjabi	White	chi-square	df	p
1	11	32	20	18.23	2	<0.001 * <sup>18</sup>
2	23	31	35	6.19	2	<0.05 *
3	9	5	20	13.77	2	<0.002 *
4	3	4	1	1.85	2	<0.40
5	10	13	17	2.52	2	<0.28

Table 8.9 shows that the significant chi-square tests of association lay with avoiding problems by ignoring them (strategy no. 1), avoiding problems by keeping busy (strategy no. 2) and eating/drinking/smoking and taking pills more (strategy no. 3). Table 8.4 clearly shows that the Gujaratis reported proportionately less use of avoidance techniques of ignoring problems than the white indigenous, and particularly the Punjabi carer groups. Past research has shown that avoidance coping strategies may be adopted in perceived negative life situations that cannot be improved (Collins *et al.*, 1983). Caring for an older person, which may be long term, might provide such a scenario (see Table 6.7) Again, possible contributory factors may be that significantly more communication problems and significantly higher perceived stress levels, generally lower levels of morale and the provision of higher levels of support mean that some Punjabi carers have no power to change their situation and therefore have no other option but to ignore problems.

Proportionately fewer Gujaratis avoided problems by keeping busy than either the Punjabi or white indigenous carers (see Table 8.4). One possible explanation for this may be that, as

<sup>17</sup> Coping strategy numbers used are the same as those in Table 8.3.

<sup>18</sup> \* denotes a significant finding.

the Gujarati group perceived less stress than the white indigenous and Punjabi carers, they did not feel the need to keep busy in order to cope. The significant chi-square test of association concerning eating/drinking/smoking/taking pills, not surprisingly, derives mainly from the difference between the white indigenous carer group and the Gujarati and Punjabi carers, who tended not to use these particular techniques (see Table 8.4).

### **8.2.2.3 Summary of Carers' Use of Active and Avoidance Mechanisms**

The information above largely demonstrates how carers might use a mixture of both active and avoidance mechanisms in their caring role. It is clear that there are some significant associations between the three cultural groups, both in overall coping strategies used, and in terms of active and avoidance methods employed. Given that active coping mechanisms are considered a more positive approach to coping, it is not surprising that the Punjabi group, who used less active coping strategies but proportionately more avoidance mechanisms, should also perceive themselves as not coping as well as either the Gujarati or white indigenous groups (see section 8.2.1). Hence, part b) of hypothesis 3 on coping is also supported in that there is a significant difference between the three cultural groups in internal coping mechanisms employed.

### **8.3 Carers' External Coping Strategies**

This section explores carers' external coping strategies, which is the final part (c) of hypothesis 3 outlined in Chapter Five. The external coping mechanisms used by carers in all cultural groups may involve a reliance on others for help and support. Amongst major factors which are believed to help carers to cope are those of time off from caring duties (e.g., someone else taking over the responsibility to care for a while), receiving services, and feelings of satisfaction with help from others in their informal network (see Chapter 4,

section 4.5). As this part of the chapter involves the different elements of support to carers, it is sub-divided into three main parts. It firstly looks at carers' time off from caring. Following this, the help, support and advice received by the different groups of carers from professionals and service providers is examined. Also investigated are reasons why carers do not necessarily ask for help from formal agencies and why they may therefore feel a need to expect more help from their informal network in the care they give to older people.

### 8.3.1 Time Off from Caring

In order to determine the time off carers received, the respondents were asked whether they regularly got a break from their caring activities (see Q.63, Appendix 1). Overall, as many as one third (n=52, 35%) did not get any kind of respite. At the same time, it needs pointing out that some of the carers in all cultural groups did not want a break from their caring activities:

*I love my husband. He is everything to me. I don't want to be away from him.*

(female Punjabi carer)

*Mother-in-law has lived with me for many years. We always get on well. We still do many things together. I would miss her, I don't like her to be away.*

(female Gujarati carer)

*I don't look at what I do for her like that. She is my life's companion. That's what life is all about.*

(male white indigenous carer of his wife)

These comments indicate that, although time off from caring may help the large majority of carers to cope, not all carers would benefit from being apart from the older person they are looking after. The qualitative evidence also bears out the fact that many carers view caring as a positive experience (Kramer, 1997; Noonan and Tennstedt, 1997). It also shows that

many older people are valued within their families (Coleman, 1992). As indicated in Chapter 4 (section 4.2.1), much depends on the way individuals perceive a potentially stressful situation. Not all carers would regard the centrality of caring in their lives as one that is harmful. As argued by Kramer (1997), caregiving tasks may be adapted to become part of one's goal in life and may therefore be perceived as benefits or gains and thus be perceived in a more positive light (see also Chapter 7, section 7.2).

Equally, many carers from all the cultural groups did want some time off from caring, but did not receive any:

*You must be joking. I never get away from it. Mum doesn't go anywhere. She refuses to, and there's nobody else to look after her. I'd love just to go shopping on my own.*

(female white indigenous carer)

*I can go nowhere. I am here all the time to look after her.*

(female Punjabi carer of her mother-in-law)

*I don't get a break. Father can be very demanding. Anyway, I get used to it.*

(female Gujarati carer)

Two thirds of the carers did regularly get a break (n=98, 65%). Here, no real differences in the Gujarati, Punjabi and white indigenous groups were apparent from the data (n=30, 60%; n=31, 62%; n=37, 74% respectively). Given that the majority of carers co-resided with the older person they were looking after (n=102, 68%), and that the majority of these were Gujarati and Punjabi carers (n=38, 76%, n=40, 80%, respectively, see Table 6.12), it became informative to see firstly, whether carer co-residency was associated with carers receiving a break (see Table 8.10). Secondly, it was interesting to explore whether there was any association between co-resident carers receiving a break and ethnicity.

**Table 8.10 Carers Receiving a Break by Same Household or Elsewhere**

Regular break	Same household	Elsewhere	Total
Yes	59 (58%)	39 (81%)	98 (65%)
No	43 (42%)	9 (19%)	52 (35%)
Base	102 (100%)	48 (100%)	150 (100%)

chi-square=7.90, df=1, p<0.005

Table 8.10 shows that there is indeed a significant association between receiving a break and whether the carers co-resided with the older person. The reason for this outcome lay with the fact that the majority of carers who did not co-reside with the older person received a regular break (n=39, 81%), whereas over a half of carers who lived in the same household reported the receipt of a regular break (n=59, 58%). Therefore, the data clearly show that co-residing with the older person means that there is significantly less opportunity for a break. This is not a surprising finding given the fact that, in this study, almost one half of co-resident carers reported spending over 100 hours per week on caregiving activities (n= 47, 46%, see Table 6.16). This would not only include the more physical tasks of caring, it would also include supervision. Clearly, carers who co-reside would also be expected to be around the older person more than those who live elsewhere.

One general comment that describes the situations of many co-resident spouse carers was:

*I can't really go anywhere without him. If he does nod off for an hour or two, I nip out and do the shopping, but all the time I'm worried if he's all right. If he wakes up before I get back, he gets upset that I'm not there, because he expects me to be there. It would be nice to have someone I could rely on to stand in for a few hours.*

(female white indigenous carer of her husband)

Filial co-resident carers also experienced problems in getting some kind of break:

*I am the only one at home to look after mother. She doesn't go anywhere during the day because it is very difficult to take her anywhere without a car, and she refuses to be left on her own, even for a short while. When my husband comes home in the evening, I need to be there for him. If we do go out, we go out as a family and of course mother comes with us.*

(female Gujarati carer of her mother)

The fact that many co-resident carers reported that they did not get any break even for just a couple of hours was not surprising. The GHS (1985) also showed that considerably more carers devoting at least 20 hours per week to caring, who lived in the same household, found it either very difficult or fairly difficult to arrange for an alternative carer for 2 hours than carers who lived elsewhere (15% as opposed to 2% respectively). It is disturbing that those most heavily involved do not get a break. Indeed, further analysis of the data showed that almost one half of co-resident carers in the present study who were caring for 100 hours or more per week did not actually get a break (n=20, 42%). As indicated earlier, providing care to an older person for a substantial number of hours increases carer burden (Stoller and Pugliesi, 1989), which in turn may negatively transform the relationship to the point where caring occupies virtually the whole of the relationship, which in turn may affect their coping ability and thus result in carers having to give up their caregiving role (Pearlin *et al.*, 1990; Aneshensel *et al.*, 1993).

The data concerning whether co-resident carers received a regular break or not were also examined in terms of ethnicity. A chi-square test of association showed that there was no significant relationship between co-residency, the receipt of a break and Gujarati, Punjabi and white indigenous carers (n=21, 36%; n=22, 37%; n=16, 27% respectively). This indicates that the lives of co-resident carers may be universally restricted as carers in all

cultural groups share the limitations that influence the lives of those they care for (Twigg and Atkin, 1994). At this stage, it is interesting to investigate whether, for those carers who did receive a break, there were any differences in the type of break carers received. Short breaks consisted of the older person attending a day/social centre, and sitters (either family or friends) taking over for a short while. Longer breaks were defined as a break of at least two days with one overnight stay, weekends away from the caring role, holidays and the provision of respite care received.

Carers' responses could therefore be separated into two main categories. Here, the data did suggest some apparent differences between the three cultural groups. Hence, a chi-square test of association was employed to investigate the relationship between the type of break received from caring and ethnicity.

**Table 8.11 Type of Break Carers Received by Ethnicity**

Break received	Gujarati	Punjabi	White	Total
Short break (up to 2 days)	26 (87%)	30 (97%)	20 (54%)	76 (77%)
Longer break (2 days or more)	4 (13%)	1 (3%)	17 (46%)	23 (23%)
Base	30 (100%)	31 (100%)	37 (100%)	98 (100%)

chi-square=19.75 df=2, p=0.000

Table 8.11 shows that the chi-square test of association is highly significant, demonstrating that there is an association between the type of break received and the three cultural groups. An overwhelming number of Gujarati and Punjabi carers received only a short time off from their caring responsibilities (n=26, 87%; n=30, 97% respectively), whereas almost one half of the white indigenous carers (n=17, 46%) got a longer break. One explanation for this

significant finding could be that, as the majority of Gujarati and Punjabi carers co-resided with the older person, they would find it more difficult to arrange a longer break (see Table 6.12). Closer examination of the data revealed that over half of white indigenous carers (n=11) who got a longer break were in receipt of respite care (see Chapter 2, section 2.4.1). In comparison to this, only one Gujarati and one Punjabi carer who had a longer break received respite services. Possible explanations for this discrepancy could be that, either the Asian carers and/or the older person in their care did not want respite service, or it was considered culturally inappropriate, or insufficiently culturally sensitive. Another explanation could be that Asian carers were unaware of this service and/or were never offered it (see Chapter 3, section 3.6).

### **8.3.2 Support to Carers from Formal Sources**

This section explores the issues surrounding formal services received and how these service provisions were perceived by the three different cultural groups involved in this study. Services are divided into community care based services, carers' support/voluntary groups and housing authority/benefits services. All are examined accordingly. The components of community care based services such as regular visits by professionals and home-care services are examined first.

#### **8.3.2.1 Support to Carers from Community Based Services**

Almost half of all the carers (n=72, 48%) in this study regularly provided a high level of support to the older person (see Table 7.5). Importantly, over one half of the carers (n=78, 52%, see Table 7.16) gave help with personal care and over two thirds gave help with physical care (n=101, 67%, see Table 7.17). Given the heavy involvement of these carers, one might have expected that older people and their carers would have regular contact with basic health and social care professionals such as the GP, community nurse, health visitor

and social worker, even if this was only to ensure carers were coping. Despite this expectation, results showed that equal percentages of older people who co-resided and who lived elsewhere (n=47, 46%; n=22, 46% respectively), did not receive regular visits from basic health and social care professionals. On the one hand, a few of the carers in all cultural groups expressed no need for some of the services. On the other hand, some of the carers reported that they had never approached, nor had ever been approached by health and social care providers. However, the data collected did not reveal whether these carers actually perceived a need for these services.

The GHS (1990) does not report whether the carers who did not receive regular visits from health and social care providers required such services. Nonetheless, it does show that almost three quarters (73%) of carers residing in the same household as their dependant and almost one half (49%) living elsewhere also did not receive regular visits from basic health and social services. As indicated in Chapter 6, although the data is not directly comparable, it does show that in this study proportionately more co-resident carers did have regular contact with these services. One explanation might be that older people, rather than children requiring care who would also co-reside, are less physically able to visit professionals such as the doctor and health visitor.

Of those older people who did regularly see basic health and social service professionals (doctor, community/district nurse, health visitor, social worker) at least once a month (see Q. 27, Appendix1), just over one half were visited regularly by only one of these professionals (n=44, 54%), but only one was seen by four. More detail regarding the contact older people from the different cultural groups had with basic health and social service providers is given in Table 8.12.

**Table 8.12 Regular Visits by Health and Social Service Professionals by Ethnicity**

Visits by professionals	Gujarati	Punjabi	White	Total
No visits	27 (54%)	9 (18%)	33 (66%)	69 (46%)
One professional	12 (24%)	20 (40%)	12 (24%)	44 (29%)
Two professionals	9 (18%)	11 (22%)	5 (10%)	25 (17%)
Three professionals	2 (4%)	9 (18%)	0	11 (7%)
Four professionals	0	1 (2%)	0	1 (0.7%)
Base	50 (100%)	50 (100%)	50 (100%)	150 (100%)

The table demonstrates that only just over one third of white indigenous older people were visited regularly by basic health and social care professionals (n=17, 34%). Of the Asian groups of older people almost one half of Gujaratis (n=23, 46%), but over four fifths of Punjabis, were regularly visited (n=41, 82%). This latter group was also the group that were given a high level of support (see Table 7.5), which may account for the fact that they had contact with more basic health and social care professionals than the Gujarati group of older people, in particular, who were given a significantly lower level of support.

Exploration of the data on all older dependent people and regular visits from basic health and social care professionals showed that over one third (n=60, 40%) were visited by a doctor. The GHS (1990) reports that only 16% of carers with dependants received such a visit. It may be that older people needing care are less able to get to the doctor. On the other hand, it could be that older Asians in particular are more likely to suffer from a chronic illness (Boneham, 1989 and see Chapter 3, section 3.4). Yet another explanation might be that poor communication and the non-understanding of the consultation require more frequent visits (e.g. Pharoah, 1995). Differences between the cultural groups showed that

two thirds of those in receipt of a doctor's care were Punjabi older people (n=40, 67%). Less than a quarter of Gujarati (n=12, 20%) and just over one tenth of white indigenous older people (n=8, 13%) accounted for the remainder. A chi-square test of association was therefore employed to test this relationship.

**Table 8.13 Visits from the Doctor by Ethnicity**

Visits from the doctor	Gujarati	Punjabi	White	Total
Yes	12 (24%)	40 (80%)	8 (16%)	60 (40%)
No	38 (76%)	10 (20%)	42 (84%)	90 (60%)
Base	50 (100%)	50 (100%)	50 (100%)	150 (100%)
chi-square=50.67, df=2, p=0.000				

The chi-square test shows that there is indeed a highly significant association between visits by the doctor and ethnicity. Clearly, the Punjabi group of older people received more visits from a doctor than the Gujarati, and particularly the white indigenous older people. As doctors (particularly GPs) are often seen as gatekeepers to other services, this may help to explain the fact that Punjabi older people were in contact with a wider range of basic health and social care professionals than were Gujarati and white indigenous older people.

It has been shown that many of the older people being cared for were in regular contact with the doctor; thus it is pertinent to see how the carers of older people viewed this service. Examination of the interview schedules showed that an overwhelming number of carers in all cultural groups referred to their GP when asked about service provision (see Q.37, Appendix 1). As previously indicated, the GP may often be the first point of formal service contact for people (Hospital Plan for England and Wales, 1962, Cmnd. 1604). Indeed, most of the Punjabi carers found their GP to be helpful:

*Doctor, he is the only person I see myself. He is the only person I confide in.*

(female Punjabi carer)

Although many of the Punjabi speaking carers trusted their GP, and were satisfied with the services, they nevertheless encountered problems with communication and culture. As described by one carer:

*The service offered by the doctor is satisfying when it comes to treating asthma or arthritis, but when it comes to depression and stress, it is very hard to explain to the doctor- personal problem and family problem. It is hard to express how I feel.*

(female Punjabi carer of mother-in-law)

For this particular carer it was clear that language and/or cultural barriers were a difficulty in accessing specific psychological/medical advice or help if and when needed. It is therefore perhaps not surprising that, in South Asian groups, mental health problems are less recorded than they are for the white indigenous community and not necessarily thought of in terms of social dysfunction as indicated by Rack (1982). In addition, if carers are prepared to discuss sensitive issues such as stress, anxiety and feelings of depression, yet are unable to do so because of either linguistic or cultural barriers, then the lack of necessary help will mean the coping abilities of some carers will be negatively affected.

Most of the carers from all three cultural groups appeared to have a good relationship with their GP. Carers reported they found their doctor to be approachable and sensitive to their feelings, willing to listen and offer advice. In spite of this, some carers felt that the family GP was unable sufficiently to explain the older person's condition to them, particularly in relation to senile dementia:

*I didn't understand her condition at first. The GP didn't explain her condition for about six months. No information was given initially.*

(female white indigenous carer of her mother)

Naturally, being unaware of the older person's true state of health has other implications for care. Consequently, if information is not forthcoming, the carer may feel unable to begin to cope with the situation. As explained by one female white indigenous carer of her mother:

*They downplayed her condition so I was unable to get help. I was fobbed off with promises of assessment which never arised. I had to make a fuss. I looked the stupid one.*

Nonetheless, a few of the carers reported that the GP had referred them to other agencies in order to get the help they needed. No major reservations were expressed about the community nursing service or indeed other professional health carers other than how long it took to be seen by them. None of the carers in this study reported an unwillingness of the older person they were caring for to be in contact with the GP, although this was not the situation with other agencies. It was apparent from the interviews that the home-care services (the most valued social service provision, see Chapter 2, section 2.4.1) did not always prove to be entirely suitable. This service was used by a quarter of older people and their carers (n=37, 25%), and is very similar to the percentage in the GHS (1990) who also reported using a home help (23%). In this study, over one half of those who used this service were Gujaratis (n=20, 54%), whereas almost one third were white indigenous (n=12, 32%), but only just over one tenth were Punjabi older people and their carers (n=5, 14%). Differences in the use of the home-care services in the three cultural groups can be demonstrated by the carers' comments:

*The home-help was not very good. She didn't clean thoroughly enough. It upset Mrs. Smith<sup>19</sup> that her home was deteriorating around her. She stopped it, but that meant that I needed to do more for her. I don't mind, but it means that I have even less time for my kids and husband. They are beginning to feel neglected.*  
(female white indigenous carer caring for her neighbour)

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<sup>19</sup> The name has been changed to protect anonymity.

*We had to stop the home-help. She was not very good and she complained about the smell of Indian food in the house. We felt very uncomfortable.*

(female Punjabi carer of her mother-in-law)

Both of these carers and the older people they were looking after had bad experiences with the service. Home-care services are by their very nature a very personal service. Older people and their carers invite these agencies into their home and will pay for a service, which is meant to make their lives easier. It does seem a great pity that it does not always live up to its expectations. Nonetheless, where it matches expectations it is also highly valued (Fry, 1988 and see Chapter 2, section 2.4.1), as related by this carer:

*We find the home-help very good. She is kind and will do things for Mum in her own time. She is also great company for Mum when she is there.*

(female Gujarati carer)

The data and quotations above particularly demonstrate the difference in take-up and opinions regarding home-care services between the Gujarati and Punjabi groups. It is not clear whether many Punjabi older people and their carers either actually needed or even wanted the service, which would help to explain this difference. On the other hand, one explanation may be that Gujarati older people and their carers had been matched to home carers/helps from the same ethnic group and Punjabis had not. Culturally specific service provision may therefore be an influencing factor in the take-up of personal services such as home-care.

During the interview, carers were also specifically asked which services they found especially helpful (see Q.37, Appendix 1). As indicated above, the Punjabi carers found their GP to be most helpful. Interestingly, the most useful service for the Gujarati group were community professionals, such as Asian community workers:

*The social worker connected to my group is very helpful. She has helped me to get my mother into a day centre and has helped me to get benefits. She always explains.*

(female Gujarati carer of her mother)

One overwhelming finding, which became apparent during detailed examination of the interview schedules, concerned the differences in the type of formal service providers used by the two minority ethnic groups. Many of the carers in the Gujarati group specifically mentioned the ability to communicate easily with a wider range of care professionals who could understand them and their way of life. This therefore indicates an ability to access different services (other than basic health and social services), whereas it appears that Punjabi carers tend to rely on a more limited group of formal agencies (such as their GP). Indeed, the most common complaints from the Punjabi carers, in particular, concerned the non-understanding of their culture and communication difficulties with some health and social care workers:

*They serve vegetarian food, but it is cooked in pans used for cooking meat. Then they ask why we don't want it. They don't understand how this is important to our culture.*

(male Punjabi carer of his wife)

*I think I speak English well, but they say 'pardon, pardon'. I try to explain again, but then I stop and go away without what I came for.*

(female Punjabi carer of her father)

The ability to communicate with service providers and thereby access services that are more specific is essential. A high number of white indigenous carers found specialist services, for instance electronic devices to summon help, extremely useful. This demonstrates a better awareness of the white indigenous group of help available to carers in the community. Another form of formal support to carers is that of voluntary organisations. How these groups are accessed by the different samples of carers is the next issue to be discussed.

### **8.3.2.2 Voluntary and Carer Support Groups**

In Chapter Two of this thesis, government objectives regarding the inclusion and promotion of voluntary organisations in the care of older people were outlined (see Chapter 2, section 2.3.1; Chapter 3, section 3.6.1). It was therefore considered pertinent to enquire of carers how much they knew of such organisations, how much contact they had with carer support groups (see Q.44, Appendix 1), whether they were themselves involved in any voluntary work, and if so, whether this was related to caring.

Examination of the data showed that carers' knowledge of voluntary groups on the whole was fairly limited. Nearly two thirds (n=94, 63%) knew of very large national organisations such as Age Concern, but less of the more specialised ones such as Arthritis Care, unless the carers themselves had contacted them for information regarding the older person's condition. Where carers had spoken about contact regarding information, almost all expressed satisfaction with the material presented to them.

Asian carers, in particular the Punjabi carers, were well aware of local Asian groups they could visit or contact. Indeed Punjabi carers (n=39, 78%) were the group who were most in contact with their local Asian group. Fewer Gujarati (n=15, 30%) and even fewer white indigenous carers (n=7, 14%) regularly contacted their local voluntary groups. This is not to say that carers did not use the various voluntary organisations, it rather appears that many carers would only contact them for specific information as and when necessary. Nonetheless, the fact that over three quarters of Punjabis made use of their local group as opposed to only three tenths of Gujarati carers is an interesting finding. One explanation for this difference might be that Punjabis were less able to communicate satisfactorily with wider society given the previous findings on language problems. This important factor may also partly provide some answers to the possibility of acculturation in the Gujarati group of

carers (see section 8.2.2). Clearly, the reasons for communication problems and their impact on the Punjabi community need further detailed research.

Some gender differences in knowledge and contact with voluntary groups were also discerned. Proportionately more women than men used such groups (n=82, 68%; n=18, 62% respectively) and in general were more aware of their availability. Women in particular (white indigenous) used the local carers' centre in Kettering, which could easily be accessed by female carers while they were out shopping:

*The carers' centre is really handy for me. I can just pop in any time I'm in town doing my shopping. They will talk to you about anything, it's all confidential. They try to help you as much as they can. It's you that's important there, not my husband so much. It's me they listen to. I can have a good nag and a moan. I can't tell you how good that feels!*

(female white indigenous carer of husband)

Although proportionately more white indigenous female than white indigenous male carers contacted voluntary groups and carer support groups, the numbers were more equal in the Punjabi and Gujarati speaking communities. Here, there was more of a family involvement in a more social atmosphere. Although the local Asian groups were largely voluntary (with some funding by local authorities), they were more of a meeting place where Indian food was prepared and cooked, rather than run specifically for older people or carers.

All carers were asked whether they were, or would find it useful to be, in contact with a voluntary/carers' support group (see Q.46, Appendix 1). Two thirds of all carers answered positively. Almost all Punjabi carers (n=44, 88%) felt it would be useful to them. Nearly three quarters of Gujarati carers (n=37, 74%) were interested; however only just over a third of white indigenous carers thought there would be any benefit in it for them. Clearly Asian

carers wished the opportunity for help and advice from such a source if it were more available to them. This finding is consistent with previous literature which has found that general voluntary services are not ethnically sensitive (Walker and Ahmad, 1994 and see Chapter 3, section 3.6.1). The evidence provided has shown that Punjabi carers in particular need to rely on their own community groups for basic help. However, this help can only be extended if either health and social service providers become more culturally sensitive so there is no need for Punjabis to rely on their own community so much, or more resources are made available to Asian voluntary groups from local authorities, who also have spending limits. This therefore also brings up the debate on whether special provisions should be made for minority ethnic communities, which in itself may be seen as an example of racism (Atkin, 1992). It can be argued that making special provisions to Asian groups, such as the Punjabi community, is the only way to ensure an equitable service. On the other hand, it might be considered discriminatory in that other groups and community-wide voluntary services may not be able to meet the needs of their clients who are equally deserving (see Chapter 3, section 3.5).

One of the main reasons for some carers not wishing to participate in a carer support group was other family commitments. Marginally fewer carers were happy with their caring role and/or could foresee no benefits by being involved in such a group. As expressed by a white indigenous carer looking after her mother:

*I don't see much point in it for me. I get on well with Mum. We've always had a good relationship. In fact, I think that if she thought I needed to talk to somebody about her she would be really upset. It would destroy the trust and the relationship.*

Five carers said they could not leave the older person in their care, even for a short while (see section 8.3.1 above). Three carers had used such a group previously, but found they

were either badly managed or they did not feel any joy in seeing others worse off than themselves. The feelings expressed were:

*The same people always had something to say. The man running the group didn't stop them, but none of us others got a chance. In the end, they were running the group rather than him. A waste of time.*

(male white indigenous carer of his wife)

*It got me down in the end. One poor old soul couldn't do anything, she just sat there and dribbled. Her husband was marvellous, but it was obvious he couldn't carry on much longer.*

(female white indigenous carer of her mother)

As this qualitative evidence shows, carer support groups may not be useful to all carers. On the whole though, most carers in all cultural groups expressed an interest in carer support centres and groups when available to them, if only to obtain specific information and advice, rather than use them regularly as a circle of friends or as a means of counselling.

All of the primary health and social care agencies discussed above are clearly important sources of social support to many of the carers in this study, and address the five components relating to emotional support, cognitive guidance, socialising, tangible assistance and availability of someone to confide in that meet basic individual needs (see Chapter 4, section 4.5). The following section now focuses on the more secondary social agencies that may help carers to cope.

### **8.3.2.3 Local Housing Authority and Benefit Services**

This section on help from formal sources looks at the kind of support received by older people and their carers from local housing authorities and benefits services. Housing will be examined first.

Although the housing of older people not living with their carer was not a main focus of this research, several of the Asian carers reported particular problems with the type of accommodation provided to older people by local authorities, which affected their ability to cope. Cultural norms regarding the extended family still play an important role for many of the Gujarati and Punjabi carers in this study. Indeed, as shown in Table 6.12, many older Asian people co-resided with their carer. Nevertheless, living together may not always be a viable situation. A few of the carers (non-spouse) reported that either they, or the older person living with them, would have felt happier for the older person to live elsewhere. This could be more independent living in a warden controlled flat/bungalow, or being cared for in a residential/nursing home for older people. In particular, Punjabi carers commented that this kind of culturally specific accommodation was not accessible to them and did not exist in Northamptonshire. As expressed by one Punjabi carer looking after her mother:

*I would feel happier if my mother could stay at council flat or accommodation with warden. I wish we had a place like Gharana<sup>20</sup> where the elderly people can have Asian meals, staff and social worker who understand their problems and deal with them.*

Even when council accommodation was available to older people, carers complained about its suitability:

*My mother-in-law has been given a council flat, but it is on the third floor. There is no other person who lives on the floor. She gets very frightened at night. If something happens there is nobody to talk to, or to ask for help. I have asked about her being moved, but nothing has been done about it. She is very lonely and depressed. Nobody goes to see her, because of the stairs and it is difficult to get up there.*

(female Punjabi carer of her mother-in-law)

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<sup>20</sup> The Gharana Housing Association is local authority funded, Gujarati speaking, warden controlled accommodation for older people.

This particular carer found it increasingly difficult to cope with constantly being called to be with her mother-in-law who wanted more independence. Unsuitable council accommodation for older people supported by the white indigenous group of carers was also mentioned:

*The council don't consider what age groups they put together. They have put noisy younger people above her flat and they don't take any notice of complaints.*

(female carer of her mother)

Older people may wish to retain more independence even though they require some form of care. Unsuitable housing can only make older people feel more vulnerable and incapable and therefore add concern to the carer's role and ultimately their ability to cope. Inevitably, it may also increase the possibility of the need for further dependence by older people on others. In addition, it is important to note that many carers (particularly white indigenous carers) are themselves older. In this study, it was found that 14% of carers in this group were aged 71 years or more (see Table 6.2). Clearly, unsuitable accommodation affects not only the older person receiving care, it also affects the ability of the carer to cope.

This next section examines another side to formal services to older people and their carers, namely that of benefits available. Research has shown that many carers may suffer financially as a result of their caring role (Glendinning, 1992). Although the economic effect of caring was not a main focus in this project, it has been found to be an important secondary stressor (Pearlin *et al.*, 1990) and inevitably affects how carers of older people may cope with their caring role. Therefore, some brief discussion is warranted here.

In this study, the majority of carers did not know, or wish to disclose, personal information regarding their household income. Furthermore, some carers, particularly Asians, were not necessarily aware of exact benefits received by the older person they were looking after.

Therefore, only the benefits received by the carer, or reported costs to the carer and/or benefits known to have been received by the older person, can be detailed, along with any problems in obtaining such benefits.

Other than retirement pensions there are state benefits available to older people who are disabled or who need care (dependant on certain criteria). This information is given in Table 8.14.

**Table 8.14 Benefits Available to Disabled Older People**

Benefit available	Criteria on which benefit is based
Attendance allowance	For those aged 65 years and over who need help with personal care because of illness or disability. Help must have been needed for at least 6 months
Disability living allowance (care component) (mobility component)	For those aged under 65 years who need help with personal care, getting around, or both because they are ill or disabled. Help must have been needed for at least 3 months and likely to be needed for at least another 6 months.
Incapacity benefit	For those of employment age and dependent on NI contributions.
Severe disablement allowance	For those aged 16-65 years, unable to have worked for 28 consecutive weeks And unable to get incapacity benefit.

Carers at present are only eligible for one benefit, namely the invalid care allowance. This may be applied for by carers aged 16-65 years, looking after someone for a minimum of 35 hours per week who receives the middle or highest rate of disability living allowance or attendance allowance. Carers may not be in full-time education, nor earn more than fifty pounds per week after allowable expenses. This benefit is one of the lowest state benefits

available at £38.70 (April, 1998). Furthermore, should the carer of an older person have other dependants, such as a disabled spouse receiving benefit, the carer him/herself is means tested to qualify for any additional benefit.

In this study, it was reported by carers that almost half of all older people (n=67, 47%, see Table 6.9) received an attendance allowance, yet only eighteen carers (12%) were in receipt of the invalid care allowance. One explanation for such a small number of carers receiving this benefit may be due to the fact that many carers lose it because of overlapping benefit regulations (McLaughlin, 1991). Some cultural differences were also evident though not statistically significant. The largest group of older people receiving an attendance allowance were the white indigenous (n=28, 42%). The smallest group were the Punjabi older people who accounted for only a quarter of this benefit (n=17, 25%), yet this was also the group who were given a high level of care (see Table 7.5). No comparison can be made to national data as older people in need of care in this study were classified as 55 years of age and over. Table 6.7 shows that almost two thirds of older people in this study were aged 55-75 years; therefore it is difficult to discern how many may have been eligible.

Carers were asked whether they, or the older person in receipt of their care, had any problems obtaining benefits. Carers reported particular difficulties with obtaining the attendance allowance:

*We made three attempts to get attendance allowance; we needed to push it. If you don't know to be persistent, you can lose out.*

(female white indigenous carer caring for her father-in-law)

Understandably, the group who reported the most difficulties with obtaining attendance allowance was also the group who received it the least (n=17, 25%):

*To get the benefit, it was a struggle. The only way we got it was through social workers. They told me it was difficult.*

(male Punjabi carer looking after his mother)

Given that benefits appear, at times, difficult to obtain, especially for some minority groups, it is perhaps no wonder that as many as eight Punjabi carers reported that the older person they were caring for was financially dependent upon them. As well as language barriers, issues such as pension entitlement, means testing and immigration policies may have played a role here (see Chapter 3, section 3.3.1).

Not surprisingly, almost a quarter of carers (n=33, 22%) reported that they did not perceive having enough income to care satisfactorily. Of these, the great majority were Gujarati and Punjabi carers (n=15, 45%, n=14, 42% respectively), whereas only four (12%) of the white indigenous carers thought they did not have sufficient income to care satisfactorily. As reported by some of the Gujarati and Punjabi carers:

*I try to make sure he is comfortable even though it's hard at times. If he really knew how I struggle it would upset him very much..*

(female Gujarati carer of her husband)

*It is hard to get everything he needs. I don't have enough money for all the things.*

(female Punjabi carer of her husband)

This section has looked at some of the different formal sources of support available to informal carers in the three cultural groups. There have been many similarities and differences in these provisions. Thus, it now becomes interesting to combine the experiences of the carers and assess their happiness with the varying services they have been in contact with (see Q.43, Appendix 1). Although carers will undoubtedly have had different feelings

about different formal contacts, an overall scale of their happiness is relevant to see how external mechanisms help carers to cope.

In order to be consistent with previous measures of perceived stress and coping in this study, carers were asked to respond to a five point rating scale from not very happy (1) to very happy (5) with support from formal sources. Table 8.15 tabulates the information for the three different cultural groups.

**Table 8.15 Happiness with Help from Formal Sources**

Level of happiness	Gujarati	Punjabi	White	Total
1 Not very happy	4 (8%)	2 (4%)	3 (6%)	9 (6%)
2 Not happy	3 (6%)	11 (22%)	7 (14%)	21 (14%)
3 Neither not happy/nor happy	10 (20%)	21 (42%)	14 (28%)	45 (30%)
4 Happy	15 (30%)	11 (22%)	13 (26%)	39 (26%)
5 Very happy	18 (36%)	5 (10%)	13 (26%)	36 (24%)
Base	50 (100%)	50 (100%)	50 (100%)	150 (100%)

From the total sample, exactly one half of carers (n=75, 50%) reported that they were happy or very happy with the services received from the different formal sources. Looking at each cultural group separately it was found that two thirds of the Gujarati (n=33, 66%) and just over one half of the white indigenous carers (n=26, 52%) reported they were happy or very happy with formal service contact. Conversely, only one third of the Punjabi carers (n=16, 32%) were similarly happy with formal service provision. This finding again makes the Punjabi carers stand apart from the other two cultural groups researched.

Almost one third of all carers (n=45, 30%) were uncertain about their happiness with services from formal sources and therefore described themselves as neither happy nor not happy. It therefore appears that some of the people involved in formal service provision may not have made a good enough impact on the carers they were in contact with. One contributory factor for this result might be that some health and social care professionals were not aware of other specific people or agencies carers could be referred to.

Further exploration of this data showed that the Gujarati carers were the least uncertain (n=10, 20%), followed by the white indigenous carer group (n=14, 28%). The Punjabi group were the most doubtful about their happiness with help from formal sources and consequently a higher proportion reported feeling neither happy nor not happy (n=21, 42%). In terms of those carers who were unhappy, the Gujarati sample of carers were the least unhappy (n=7, 14%), followed by the white indigenous group (n=10, 20%). However, over one quarter of the Punjabi respondents (n=13, 26%) reported unhappiness with the help received from formal sources.

Clearly, the above observations demonstrate some discernible divisions between the three groups. In order to explore this further, the data were collapsed into three categories of happiness with help from formal services: points 1-2 of the scale indicating general unhappiness, point three of the scale indicating uncertain happiness with services, and points 4-5 of the scale happiness with formal support. A chi-square test revealed a significant association between happiness with formal service support and ethnicity (chi-square=11.77, df=4, p<0.02). From looking at Table 8.15, one can see the difference lies principally with the Punjabi group of carers who were more likely to express doubt with formal service help. Although no directly comparable information exists for carers from different cultural groups, one explanation for these differences may be that Gujarati carers reported the

availability of Asian community workers with whom they were able to communicate effectively. However, this facility was not reported to be available to Punjabi carers in Northamptonshire (see section 8.3.2.1).

Research into older people from minority ethnic communities shows that Asians report problems with ethnicity related issues such as communication with health and social services (Askham *et al.*, 1995). In addition, other research has shown that the role of link/community workers skilled in a particular language is very valuable not only to the community they serve, but also to formal service providers. Link/community workers are reported to be particularly successful in 'outreach' methods of working and are able to respond flexibly to community needs, whether it is for information, advice or counselling (Pharoah, 1995). Clearly, the availability of such workers shows a concerted effort by service providers to aid minority ethnic communities in meeting their particular needs. Given that Gujarati carers appear to be able to make use of such a service, this may help to explain their higher levels of reported happiness with overall service provision, whereas white indigenous and Punjabi carers did not appear to have a particular community worker to turn to for help.

Against this background, it now becomes pertinent to examine the help carers might get from their informal network as this constitutes another valuable source of social support that may enable carers to cope.

#### **8.4 Support to Carers from Informal Sources**

In Chapter Two of this thesis, government policy concerning primary sources of support to older people, together with the emphasis on the provision of help through informal networks, was highlighted. Nevertheless, this often means a reliance on one main person,

i.e., the carer, rather than on a whole order of supportive individuals known to an older person. It is interesting, therefore, to look at what kind of help carers themselves can muster from their informal network to aid them in their role as a carer.

Carers in all cultural groups did not perceive much help from their informal network in their daily lives. Most of the help that was received came from the carers' partners and children rather than from a wider network of other family, friends, neighbours and the local community:

*My husband is brilliant. Even though he works hard, he not only helps me look after Mum, he often has to do the cooking. He helps with the housework and never complains. I couldn't cope with Mum without him. It's awkward to move her and she's quite heavy, he's brilliant with her, you know, joking all the time.*

(female white indigenous carer of her mother)

*My husband and children help with mother-in-law. Other family come to visit, but never take her out.*

(female Gujarati carer of her mother-in-law)

*My son and his family came to live closer to us. My husband needs a lot of care and I can't do it all. My son very good and helps me with many things. He is the only one.*

(female Punjabi carer of her husband)

Findings therefore suggest that the closer the relative (both in terms of relationship and distance of residence), the more likely will the availability of instrumental help be. As other work on informal care has found, proximity is the one most obvious and important factor enabling others to support the main carer (e.g. Parker, 1993a). Co-residence of a partner or adolescent and adult children is important, in that main carers do not have to ask for help, which in effect lifts one of the barriers to obtaining support. This therefore may have the

effect of reducing potential sources of stress, help with higher levels of morale, and enable carers to cope, particularly if carers are also providing high levels of support.

An interesting question here is whether carers need to ask for help from their informal network, or whether such help is offered automatically. Examination of the material showed that, for carers overall, any help received was more likely to have been offered rather than carers needing to ask. No cultural differences relating to how help was obtained were found. Nonetheless, some gender differences did become apparent. Proportionately more female carers (n=45, 37%) than male carers (n=8, 27%) needed to ask for help, whereas proportionately more male carers (n=17, 59%) than female carers (n=62, 51%) received help automatically. This kind of evidence lends support to a feminist view in that caring is not only naturally regarded as a woman's role, it is also related to domestic labour (Atkin, 1992). Therefore, unlike men, women are less likely to be perceived as in need of help with domestic tasks from both informal networks and formal agencies.

Findings from this project also showed some cultural differences with the help carers received from friends and neighbours. Ten carers in both the Gujarati and Punjabi groups responded that friends felt they should help, whereas only one white indigenous carer perceived this. Similarly, with the help from neighbours, more Gujarati and Punjabi carers than white indigenous carers reported that neighbours were regularly involved, although this was to do more with support outside the home, for example in social activities. It may be that for the Gujarati and Punjabi groups, friends and neighbours are regarded more as a community network for instrumental help, whereas for the white indigenous group, friends and neighbours are perhaps viewed separately in their own right and used more for emotional support. Indeed in this study, more white indigenous (n=38, 76%) than Gujarati (n=21, 42%) or Punjabi carers (n=30, 60%) used friends as someone to confide in. Clearly,

there is scope for further research in types of help received from informal sources, such as friends, across different cultural groups.

Although many carers reported that they did not receive help or only received little help from their informal network, most carers felt happy with the support given to them. Importantly, unlike some formal service provision, it appeared that it was often the knowledge that support was available as and when needed which was sufficient to help carers to cope. Hence, the perceived availability of help was valued more than the actual help received. One typical comment by carers from all cultural groups was:

*If I really feel I need help, I can phone my daughter. Although she lives a little distance away, and we don't always see her, I know that if there was a problem she'd do her best to help.*

(female white indigenous carer of her husband)

One of the main reasons for limited assistance from other family, friends and neighbours may be that carers, particularly spouse carers, felt that it was their duty to care. Typical comments relating to such feelings were:

*For better, for worse. You know, that's what we promised each other when we got married. It's my job to look after him, nobody else's.*

(female white indigenous carer of her husband)

*Growing old together is part of life. He needs me more now. Looking after him is my duty. It's part of life. I like to do it and he doesn't like other people to do things.*

(female Gujarati carer)

Non-spouse carers, especially Asian carers, similarly felt it was their duty to care without much help from their informal network:

*My mother is my responsibility. I wouldn't expect help from others in caring for her.*

(female Gujarati carer)

*I am expected to care for mother-in-law. The family is there, but not to help me. Only my husband sometimes will go shopping when I can't leave her.*

(female Punjabi carer)

*It is for me to do, I can't ask anyone else. It pleases my husband that I do this.*

(female Punjabi carer looking after her mother-in-law)

Nevertheless, many of the carers in all cultural groups and relationships, although happy with the support, often expressed a wish for more help from their informal network. In particular some carers of parents and parents-in-law, excluding most Gujarati carers, felt the need for more involvement from other family members in the provision of care. It became apparent that those carers who co-resided with the older person would not necessarily want help with instrumental tasks. Rather, carers asked for help with supervision so they could get out or enjoy a short break from their caring responsibilities. Carers who lived elsewhere sometimes expressed a need for other family members to ease the pressure:

*It's always me and yet my sister doesn't live that far away. She's always got an excuse or she's too busy. Yet, when she visits Dad I hear how wonderful she is. It gets on my nerves.*

(female white indigenous carer of her father)

The quotation above clearly demonstrates not only that the locus of care is often with one person, it also shows that the tensions brought on by caring for a parent can sometimes reawaken sibling rivalry, thereby pushing the responsibility to care even further on the main carer (e.g. Harris, 1998).

In order firstly to determine the amount of help carers received, scores were taken from the scales of perceived happiness with help from family, friends and neighbours as an indication

of the number of those receiving help, and whether they were satisfied with that help or not. Secondly, in order to determine how carers perceived the type and quantity of overall general help they received in their caring role from their informal network, carers were asked to respond to three separate five point rating scales (see Qs 52, 53, 54 Appendix 1) of not very happy (1) to very happy (5) (carers who did not perceive any help from these sources were rated as 0).

Table 8.16 details the total number of sources of informal help taken from the scales on happiness with the quality of help from family, friends and neighbours.

**Table 8.16 Perceived Help from Family, Friends and Neighbours by Ethnicity**

Help from:	Gujarati	Punjabi	White	Total
Family	42 (52%)	47 (41%)	45 (47%)	134 (46%)
Friends	17 (21%)	32 (28%)	20 (21%)	69 (24%)
Neighbours	13 (16%)	32 (28%)	26 (27%)	71 (24%)
No support	8 (10%)	3 (3%)	5 (5%)	16 (5%)
Base	80 (99%)	114 (100%)	96 (100%)	290 (99%)

The first observation is the number of carers who did not perceive any help from the different sources of informal support. One tenth of all carers reported no perceived support from their family (n=16, 11%). It is also apparent that over one half of all carers perceived no support from friends and neighbours (n=81, 54%; n=79, 53% respectively). It is not clear whether these carers elected not to receive any help from family, friends and neighbours around them, or whether they simply had no one to turn to. If the latter is the case, it indicates that some carers do not have the support of others around them, which means that

either they have to cope on their own, or they may need to turn to formal agencies as their only source of support for help.

Table 8.16 shows, that overall, almost half of the sources of help mentioned were from family members (n=134, 49%). Consequently, assistance to carers from friends and neighbours was of a much lesser degree (n=69, 25%; n=71, 26% respectively).

In terms of cultural differences, Gujarati carers perceived more help from their family (n=42, 58%) than did the Punjabi and white indigenous groups (n=47, 42%; n=45, 49% respectively). Punjabi carers perceived more help from their friends than either the Gujarati or white indigenous carer groups (n=32, 29%; n= 17, 24%; n=20, 22% respectively). Punjabi and white indigenous carers perceived more help from their neighbours than did Gujarati carers (n=32, 29%; n=26, 29%; n=13, 18% respectively). Although the perceived type and quality of help will be different in individual carers, it is how the groups of carers feel in general about the support from their informal network that is of interest here.

In order to gain a clearer picture of satisfaction with help from the carers' informal network of family, friends and neighbours, and in line with other analyses, the data were collapsed into three categories of perceived satisfaction. Points 1-2 of the scale indicated general unhappiness, point 3 indicated neither happiness nor unhappiness, and points 4-5 indicated happiness with the type and quality of help from these sources of informal support. Chi-square tests were applied to examine the relationship of satisfaction with the help from the different informal sources and ethnicity. Table 8.17 details perceived happiness with support from the family.

**Table 8.17 Perceived Happiness with Type and Quality of Help from Carers' Family by Ethnicity**

Level of happiness	Gujarati	Punjabi	White	Total
Unhappy	6 (14%)	13 (28%)	5 (11%)	24 (18%)
Neither unhappy/ nor happy	4 (9%)	17 (36%)	4 (9%)	25 (19%)
Happy	32 (76%)	17 (36%)	36 (80%)	85 (63%)
Base	42 (99%)	47 (100%)	45 (100%)	134 (100%)

chi-square=24.41, df=4, p<0.0001

The table shows that significantly more Punjabi carers than Gujarati and white indigenous carers reported unhappiness with the type and quality of help from their family (n=13, 28%; n=6, 14%; n=5, 11% respectively). Similarly, four times as many Punjabis as Gujarati and white indigenous carers were equivocal about the help they received (n=17, 36%; n=4, 9%; n=4, 9% respectively). Consequently, approximately twice as many Gujarati and white indigenous carers as Punjabi carers reported that they were happy with the help they received from their family (n=32, 76%; n=36, 80%; n=17, 36% respectively).

Clearly, the main difference for the significant chi-test result is that the Punjabi group of carers who did receive help, perceived less satisfaction with the help from their family than either of the other two groups.

Table 8.18 shows that, as with the satisfaction with help from the family, proportionately more Punjabis than Gujaratis or white indigenous carers felt unhappy with the help received from friends (n=6; n=1, n=2, respectively).

**Table 8.18 Perceived Happiness with Type and Quality of Help from Carers' Friends by Ethnicity**

Level of happiness	Gujarati	Punjabi	White	Total
Unhappy	1 (6%)	6 (19%)	2 (10%)	9 (13%)
Neither unhappy/ nor happy	4 (23%)	20 (62%)	4 (20%)	28 (41%)
Happy	12 (71%)	6 (19%)	14 (70%)	32 (46%)
Base	17 (100%)	32 (100%)	20 (100%)	69 (100%)

chi-square=18.52, df=4, p<0.001

The table shows that approximately three times as many Punjabis as Gujarati and white indigenous carers were neither unhappy nor happy with the help (n=20, 62%; n=4, 23%; n=4, 20% respectively). Again, twice as many Gujarati and white indigenous carers as Punjabi carers expressed happiness with the help received from their friends (n=12, 71%; n=14, 70%; n=6, 19% respectively). Clearly, the difference again lies with the Punjabi group of carers who reported less happiness with help from friends than the other two carer groups, despite the fact that they reported having more friends who gave help. One explanation here might be that Gujarati and white indigenous carers were more selective with the friends they asked for help, and therefore were more happy with that help; in other words quality and not quantity may have been the deciding factor. Interestingly, Hirsch (1980) also reports that poorer support is provided by higher density systems.

Table 8.19 shows a similar picture to satisfaction with help from the family and friends. Significantly more Punjabi carers were unhappy with the help they received from their neighbours than the Gujarati or white indigenous carer groups (n=9, n=1, n=3 respectively).

**Table 8.19 Perceived Happiness with Type and Quality of Help from Carers' Neighbours by Ethnicity**

Level of happiness	Gujarati	Punjabi	White	Total
Unhappy	1 (8%)	9 (28%)	3 (11%)	13 (18%)
Neither unhappy/ nor happy	4 (31%)	18 (56%)	3 (11%)	25 (35%)
Happy	8 (61%)	5 (16%)	20 (77%)	32 (46%)
Base	13 (100%)	32 (100%)	26 (99%)	71 (100%)

chi-square=23.74, df=4, p<0.0001

As indicated, Punjabi carers were five times more likely to be uncertain regarding their satisfaction with help from this source than white indigenous carers (56% as opposed to 11% respectively). The great majority of Gujarati and white indigenous carers reported to be happy with the type and quality of help they received from neighbours, whereas less than two tenths of carers from the Punjabi group who received help from this source reported happiness (n=8, 61%; n=20, 77%; n=5, 16%). Clearly, the Punjabi group again feel significantly more dissatisfied with such help, despite the fact that they reported the receipt of more help from neighbours than the Gujarati and Punjabi groups of carers (n=32, n=13, n=26 respectively).

The findings on satisfaction with help from informal sources have shown that, although Punjabi carers receive more help from family, friends and neighbours, they are significantly less satisfied with any help received than either the Gujarati or white indigenous carers. One explanation for this difference may be that some carers perceived that their informal network could have been more supportive, both instrumentally and emotionally. As demonstrated in Chapter 7 (see Table 7.15), over one half of Punjabi carers felt solely responsible for the care they provided to the older person. Braithwaite (1990) has argued

that being unable to share the responsibility for care may mean that carers feel overloaded, which in turn may leave them vulnerable to stress. Other work accords with this and suggests that providing support leads to stress when the provider feels overloaded (Kessler and Mcleod, 1984). Importantly though, Braithwaite (1990) also argues that carers who feel stressed will perceive deficits in their support network, no matter what level of assistance they receive. Given the fact that Punjabi carers felt significantly more stressed than the Gujarati or white indigenous carer groups, these factors provide a clear indication as to why Punjabi carers in the present research perceived significantly less happiness with help received from their informal network.

The findings on external coping mechanisms, both in support from formal and informal sources, strongly support part c) of hypothesis 3. Results have shown significant associations between external coping mechanisms and ethnicity in the three cultural groups researched.

## **8.5 Conclusion**

This final results chapter has explored informal carers of older people and their coping abilities and internal and external coping mechanisms. The qualitative and quantitative evidence presented lends support to all parts of hypothesis 3 in that coping abilities and coping strategies significantly differ between the three cultural groups researched. However, what is most striking about this outcome is that the results have shown that the reason for the significant differences overwhelmingly lies between the Punjabi carers on the one hand, and the Gujarati and white indigenous carer groups on the other.

Some of the main findings have been that the Punjabi group of carers are significantly more uncertain about their ability to cope. Further investigation into this finding revealed that

there was a significant association between high levels of care given and perceived coping ability in the Punjabi carers researched. Given that this group provided higher levels of care and also perceived lower levels of morale and significantly higher levels of stress, it is not surprising that the Punjabi carers participating in this study also perceived uncertain coping abilities.

In relation to carers' internal coping mechanisms it was found that there was a significant difference between the use of active and avoidance mechanisms in the three cultural groups. Proportionately more Gujarati and white indigenous carers used more active coping strategies considered beneficial to one's coping abilities, than did Punjabi carers, who employed relatively more avoidance coping techniques. One possible explanation for this, which deserves more detailed research, is that more acculturation has taken place in the Gujarati group than in the Punjabi community, the former also tending to rely more on their own network for help.

Exploration of the different carers' external coping mechanisms revealed that, in terms of time off from caring, significantly more white indigenous carers received a longer break than either the Gujarati or Punjabi carers. This is a factor considered important in helping carers to cope, and given the significant difference in breaks received between Asian and white indigenous carers, this clearly needs to be addressed urgently by service planners and providers.

Support from formal sources also varied between the three groups. Here it was found that Punjabi carers tended to rely on a more basic health and social care service provision than the Gujarati and white indigenous carer groups. Communication abilities appeared to be an influencing element here, and this factor again needs to be urgently addressed if service providers wish to provide an equitable service.

In terms of help from one's informal network, more Punjabis reported to receive support than did the other two cultural groups, although they were significantly less happy with the help from family, friends and neighbours. Again, this was not a surprising finding given the interaction process between high levels of care provision, role overload, stress, and perception of support. Given that helping carers to cope with caring for an older person is of vital importance if community care objectives are to succeed, the findings from all three results chapters will now be discussed in detail.

## **CHAPTER NINE**

### **INFORMAL CARE AND ETHNICITY: A DISCUSSION**

#### **9.1 Introduction**

This thesis has focused on the situations and experiences of 50 main informal carers of older people from each of the Gujarati, Punjabi and white indigenous communities in Northamptonshire. A wealth of both quantitative and qualitative information has been collected and analysed. This chapter intends to draw together a coherent picture of the similarities and differences from the findings and associated material collated from Chapters 6-8. The conclusions derived will then lead to some suggestions for how community care planners and providers can help to design and deliver services that can be of benefit to all carers.

Essentially, there are two main strands to this chapter. In line with the main aims and objectives, it firstly discusses the circumstances of the different groups of informal carers (section 9.2). This approach provides for an initial understanding of the situations and experiences of the different carer groups. It also discerns some cultural differences in carers' characteristics that may affect their perceived morale, perceived stress, coping abilities and mechanisms.

The chapter will, secondly, concentrate on the psychosocial impact of caring. In doing so, the main findings of both the quantitative and qualitative material concerning perceived morale, stress, coping abilities, external and internal coping strategies are discussed in turn (sections 9.3 and 9.4). Again, cultural distinctions will be drawn out of the findings of the present study. Finally, this chapter will explore some of the main points collated in this study and their implications for community care policy (section 9.5).

## **9.2 The Caring Situation of Informal Carers**

This part of the chapter mainly describes and appraises the results from the socio-demographic characteristics of the informal carers (see Chapter 6). It also incorporates some of the findings that are pertinent to carers' situations such as motivations to care and possible sources of stress, as these factors have a bearing on the role of being a carer.

This study has shown there are some universal features of caring that are not dependent on cultural imperatives by demonstrating that it is the family which functions as the main source of community support for older people ( $n=142$ , 95%, see Tables 6.10 and 6.11). This finding accords with other work on general carer populations, which has found that the provision of care rests heavily on the family (Qureshi and Walker, 1989; Parker, G., 1990; Parker, R., 1990). The qualitative material presented in Chapter 7 (section 7.2) also indicated that care is embedded within the context of obligations and reciprocity (Finch and Mason, 1993; Harris, 1998). Furthermore, as evidenced in other studies on older people and their families, there was a strongly perceived normative pressure on the family, and in particular the female members, to accept caring responsibilities (Lewis and Meredith, 1988; Qureshi and Walker, 1989). This feature of caring accords with the research findings of the present study where the majority of carers were women ( $n=121$ , see Table 6.2), and the feeling of being expected to care for an older family member was universally pronounced. This was particularly noticed in the Gujarati and Punjabi carer groups where a significant majority reported that the duty to care was the main reason for assuming the caring role (see Table 7.2). Hence, many carers feel duty bound to take care of family members, such as parents and parents-in-law, and are actively encouraged to do so by community care objectives.

Clearly, the findings of the present and past research are not in line with previous government reports which have suggested that family, as well as friends and neighbours are

the bedrock of community care (Griffiths, 1988). In addition, surveys that have provided national estimates of the number of informal carers have unequivocally shown that the role of friends and neighbours as a main carer appears to be limited (Green, 1988; GHS, 1990). It does therefore appear that there is a mismatch between policy and research findings. Hence, when the government talks about community care, it actually means that it is referring to care by the family and not the wider community.

One explanation for the minimal level of support to older people from individuals other than their own family might be that, as found in other research, friends and neighbours tend to provide more infrequent and practical help and are afraid to take on more long-term commitments (Sinclair, 1990, and see Chapter 2, section 2.4.2). The findings from the present study accord with this. All the eight carers who were friends and neighbours provided practical help and kept the older person company, whereas only one provided help with giving medicines, which would imply a heavier involvement and responsibility of care. In addition, a sizeable proportion of the carers were spouse carers ( $n=38$ , 25%, see Tables 6.10 and 6.11), and over two thirds of carers resided in the same household as the older person ( $n=102$ , 68%, see Table 6.12). Therefore, there would have been less opportunity for friends and neighbours to take on the role of the main carer.

So far, some universal findings from the present study have been discussed, and it is pertinent to look for some cultural variations. In relation to co-residency, some distinct cultural differences were evident. Significantly more Gujarati ( $n=38$ , 76%) and Punjabi ( $n=40$ , 80%) than white indigenous ( $n=24$ , 48%) older people resided in the same household as their carer (see Table 6.12). It was also apparent that more Gujarati and Punjabi carers looked after a wider range of family members in the same household than did carers from the white indigenous sample (see Table 6.13). This finding therefore supports other work, which shows that the traditional extended family is still common amongst Asian families

(Fenton, 1987; Atkin *et al.*, 1989; Williams, 1990; Berthoud and Beishon, 1997). Nonetheless, wider factors such as dependency needs (see Table 6.14), communication barriers (see section 3.5.1), a lack of suitable housing (see Chapter 3, section 3.7 and Chapter 8, section 8.3.2.3) and the lower socio-economic position of older Asian women in particular may mean that there is more of a need for co-residency (see Chapter 3, section 3.3.1). As shown in the present study, over one half of those older people receiving income support were Asian women (n=44, 57%, see Table 6.9). Therefore, in addition to cultural norms, other factors may help to account for the high number of older Asians who co-reside with their carer.

Interestingly, in the present study only Gujarati and Punjabi mothers-in-law lived in the same household as their carer (see Table 6.13). The great majority of the carers involved here were female (n=27, 96%). This finding strongly suggests that the sense of duty for women from these two cultures to care for their husband's mother is very strong. At this point it is also interesting to note that the majority of carers in all three cultural groups reported to care more out of duty than love for their mother-in-law (n=30, 83%, see Table 7.1). Of course duty and love may often be used synonymously in this respect (Twigg and Atkin, 1994) and it is difficult to disentangle which might be the overriding factor in caring situations. Nonetheless, caring does take place in a relationship, and carers do not always love the parent they are caring for (e.g. Pitkeathley, 1992). However, it was also interesting to note that significantly more Gujarati and Punjabi carers overall reported to care more out of duty than love than did the white indigenous carer group (n=35, 70%, n=30, 60%, n=8, 16% respectively, see Table 7.2). It may simply be that for Gujarati and Punjabi carers the cultural traits of duty were greater determinants in caring. On the other hand, it may be that, in this instance, carers employ this kind of language to describe their caring role, as demonstrated by the significant relationship between ethnicity and motivation for caring for their spouse/partner (see Table 7.3).

The issue as to whether carers care more out of duty than love for older people may, however, be more pertinent to Asian carers given traditional Asian systems of obligation (see Chapter 3, section 3.3.3). It has been argued that a marked difference in values and beliefs exists between first and second generation Asians (Modood *et al.*, 1994), which may have indicated that younger Asians felt less duty bound to care for older relatives. However, the evidence has shown that not only is the extended family among Asians alive and well, young Asians are indeed caring for older people. At this point, it is therefore interesting to take a closer look to the age groups of the carers researched.

The findings from this research show that a significant majority of those carers aged 18-40 years were Gujarati and Punjabi (n=25, 46%, n=23, 43% respectively), as opposed to just over one tenth of white indigenous carers (n=6, 11%). Conversely, in the older age bands of 56 years and over, the majority (n=21, 57%) were white indigenous carers (see Table 6.2). However, the findings also show that many younger Gujarati and Punjabi carers are also caring for older people who are significantly younger (see Table 6.7). This may be an artefact of the sampling method; nevertheless, it has been suggested above that one determining factor in the need for co-residence in older people may be their dependency needs. Given that the incidence and severity of ill health and disability increase with age (see Chapter 2, section 2.4.2), one might have expected that the majority of older people requiring care would be of a more advanced age. However, in the present study the majority of cared-for older people were aged 55-75 years (n=96, 64%) and a significant majority of these were Asian older people (n=81, 84%, see Table 6.7). This finding therefore accords with previous literature as it indicates not only that do people from minority groups perceive themselves as ageing earlier (McCalman, 1990), but also that the incidence of disability is higher among Asians than others when standardised for age (George, 1993). This finding also provides further justification for the use of the cut-off point of 55 years and above for the categorisation of older people in this research.

Clearly, the fact that many older Asians in the present research received care at a younger age, and that many Punjabis in particular were also given a higher level of care (see Table 7.5), has important implications for service planners and providers of community care. It appears that many Asian carers will need to provide a substantial amount of care for a longer period than white indigenous carers and will therefore require adequate and appropriate services to meet their needs (see section 9.4.3 for the discussion on formal service provision).

Chapter 2 (sections 2.2 and 2.3) reviewed Government policy, which has moved away from institutional care towards a mixed provision of care in the community and towards a greater focus on the role of informal carers: i.e. the family in the provision of community care. However, the literature has also shown that informal caring can impose great financial burdens both in terms of expenses and in terms of employment opportunities incurred through caring (Finch and Groves, 1983; Ungerson, 1987; Lewis and Meredith, 1988; Richardson *et al.*, 1989; Parker, G., 1990; Glendinning, 1992; Joshi, 1992; Twigg and Atkin, 1994). In relation to the financial costs of caring, it was found that, in the present study, almost a fifth of carers had paid for home improvements in order provide more safe and effective care (n=25, 17%, see Chapter 7, section 7.6.6). This finding is in line with other research, which has shown that carers finance house adaptations so as to meet the specialised needs of older people (Glendinning, 1992). Some carers in the present study reported that they had asked for financial help with improvements from their local authority and from social service departments, but were told there were not enough resources for such major works. Therefore they had delved into their own, their family's or the older person's savings to adapt the home. Clearly, carers are prepared to incur major costs to care in the absence of financial support from formal agencies. However, this may also mean they are left with reduced financial resources to meet the more general and daily costs of caring.

In terms of recurrent household expenditure through caring, the findings from this study showed that carers who reported extra costs with the telephone, travel and laundry, were also co-resident carers (n=23, 64%; n=24, 52%; n=22, 71% respectively, see Chapter 7, section 7.6.6). The data, when explored further, shows that most carers who co-resided were Gujaratis and Punjabis. Interestingly, unlike the white indigenous carer group, the majority of co-resident carers in these latter two groups also reported that they did not incur regular increased expenditure through caring (n=18, 36%; n=28, 56%, n=37, 74% respectively). One explanation might be that many of these carers were already co-residing with the older person before the need for care arose and would consider these costs as part of the normal household expenditure. Nonetheless, the findings from the present study indicate that caring informally can impose financial burdens on individuals, which is not taken into account when the state talks about cheaper and more effective care.

Given that caring for an older person does, to a certain extent, entail extra costs, it is also important to discuss carers' earning capacity. In terms of employment opportunities, the findings from this research show that, of the carers eligible to work, almost one half were not in paid employment (n=71, 47%). Further examination of the data revealed that over one half of carers who were not in paid employment were caring for 50 hours or more per week (n=42, 59%), which is equivalent to more than 7 hours of care per day. This corroborates Glendinning's (1992) argument that, because of their caring responsibilities, many carers would find it extremely difficult to take up employment.

The data from this study also points to some cultural differences in that more white indigenous than Gujarati or Punjabi carers were in paid employment (n=28, 56%, n=22, 44%, n=18, 36% respectively, see Table 6.3). In part, this might reflect the effects of gender or age. Only two white indigenous female carers had young children, whereas more Gujarati and Punjabi females were also looking after young children (n=11, n=6 respectively). Lower

rates of female Asian carers' participation in the labour market may therefore not necessarily be due to caring responsibilities for older people. Instead, the fact that many of the female carers had children may have contributed to the fact that there was little overall difference in the number of carers working full and part-time (n=26, 21%, n=29, 24%). Nonetheless, given the fact that more Gujarati and Punjabi than white indigenous carers were not in paid employment, it is not surprising that the great majority of those reporting they did not have sufficient income to care were also the Gujarati and Punjabi groups (see Chapter 8, section 8.3.2.3). This finding accords with other work, which has argued that employment prospects in black and minority groups would affect carers' ability to afford the financial cost of caring (Williams, 1990, and see Chapter 3, section 3.3.1).

One of the main barriers to the uptake of employment may be the level of fluency in English (e.g. Robinson, 1990, and see Chapter 3, section 3.3.1). However, language and communication ability is not only an important factor for employment, but also for the uptake of services (Atkin and Rollings, 1993). The data from the present study show that the vast majority of Gujarati and Punjabi carers view their community language as their first language (n=46, 92%; n=49, 98% respectively, see Chapter 6, section 6.2.3). As one might have expected, many carers would speak their mother tongue at home, particularly to their elders who may not be able to speak English, especially older women (Bowling, 1990; Donaldson and Johnson, 1990). However, what was surprising was the significant difference in communication ability with formal service providers in the Gujarati and Punjabi carer groups (see Table 6.5). Gujarati carers reported they had more contact with a wider range of care professionals who understood them and their way of life. Gujarati carers also reported that the most useful service was provided by community/link workers who spoke their language and who also acted as their agents when dealing with other agencies (see Chapter 8, section 8.3.2.1).

Although the data was unable to reveal whether the inability to communicate effectively with formal agencies was solely due to carers' fluency in English, this finding has clear implications for service providers if they wish to make practical support to carers a priority. Service providers will need to assess properly the linguistic ability of the different cultural groups they are dealing with to ensure an equitable service, as it appears that Punjabi carers did not have the same opportunities for effective contact with formal service agents as the Gujarati carers researched (see Chapter 8, section 8.3.2.1). The implications of language as a cultural barrier is well documented (Atkin and Rollings, 1993). In the present study, it was seen that the inability to communicate effectively with others may well affect carers' situations and experiences and thereby their levels of perceived morale, stress and coping abilities.

### **9.3 The Psychosocial Impact of Informal Caring**

There is no doubt that the success of community care initiatives rests heavily on the ability of informal carers (i.e. the family) to continue in their caring role. As the findings from this study have demonstrated, most families are indeed committed to caring for older relatives, and importantly many perceive benefits as well as costs as a result of caring (Grant and Nolan, 1993 and see Chapter 7, section 7.2). Nonetheless, it is these costs of caring that are important in furthering the understanding of the caring situation, particularly in relation to carers from different cultural groups and their perceived morale, stress and coping abilities. They are also important to service providers in order to meet their objectives by making practical support to individual carers a high priority. Naturally, this also has implications for ensuring that all carers perceive the caring experience as a more positive one.

The findings demonstrated that Gujarati and white indigenous carers reported higher levels of perceived morale (see Chapter 7, section 7.4), perceived significantly lower levels of stress (see Chapter 7, section 7.5.1) and perceived significantly higher coping abilities than

the Punjabi carer group (see Chapter 8, section 8.2.1). Results also showed that there was a significant association in the use of active and avoidance mechanisms in the three cultural groups (see Table 8.5). Proportionately more Gujarati and white indigenous carers than Punjabis used active coping techniques, whereas this latter group used proportionately more avoidance coping mechanisms than the Gujarati and white indigenous carers. In terms of external coping strategies, the findings showed there were significant associations in the type of break received and ethnicity (see Table 8.11). Significantly, more white indigenous carers than Gujarati and Punjabi carers received a longer break. In terms of perceived happiness with support from formal and informal sources, the Punjabi group of carers were significantly less satisfied than the other two carer groups (see Chapter 8, section 8.3.2.3 and Tables 8.17, 8.18 and 8.19). Although morale, stress and coping are significantly associated with one another (see Table 8.1), in order not to overlook important factors in the explanation of each of these findings, perceived morale, stress and coping will be discussed in turn.

### **9.3.1 Carers and Their Perception of Morale**

Morale is a useful concept which allows for a more comprehensive understanding of adjustment in life (Palmore and Luikart, 1972). Taking on the responsibility to care for an older person clearly constitutes a situation where individuals encounter change in their lives and which they need to adapt to. Therefore, the measurement of perceived morale in carers helps to establish a clearer insight into how carers have adjusted to their role.

In Chapter 7 (see section 7.4) the findings showed that only the Gujarati and white indigenous carer groups registered the highest possible morale scores. This indicated that none of the Punjabi carers perceived very high levels of morale and tends to suggest that Punjabis have not adjusted to their overall caring role as well as Gujarati and white indigenous carers. One main explanation for this may be that the Punjabi carers provided

higher levels of care than Gujarati and white indigenous carers (see Table 7.5). As demonstrated, the provision of higher levels of care are associated with the experience of stress (see Table 7.13), which was in turn significantly related to perceived morale (see Table 8.1). In addition, Punjabi carers reported significantly more communication problems with formal service providers than did Gujarati carers (see Table 6.5). This factor may have contributed to the fact that Punjabi carers were also the group who appeared to access a more basic provision of services than the other two groups. This may have left them with more unmet needs, which again might have limited the perception of higher levels of morale.

In terms of perceived morale, the study found no statistical difference between the three cultural groups, indicating a tendency to report medium levels of morale by the majority of carers. A closer look at the data showed that more Gujarati carers reported higher morale levels than did white indigenous or Punjabi carers and these latter two groups were more than twice as likely to report low levels of morale than the Gujarati group (see Table 7.7). One important related factor to carers' perceived morale concerns that of self-rated health. Previous research has shown that an individual's concept of health is significantly correlated to morale (Palmore and Luikart, 1972). The present research accords with this, as there was a significant association between perceived emotional health and morale (see Table 7.8). This finding also revealed that over one half of all carers felt their emotional health had been detrimentally affected by caring (n=91, 61% and see Table 7.9). Some differences between the cultural groups were also evident, significantly fewer Gujaratis than Punjabi or white indigenous carers reported that their emotional health had suffered as a result of caring (n=20, 22%, n=36, 40%; n=35, 38% respectively).

It is not clear which factors in particular may have contributed to these findings. However, one explanation may be that significantly more Punjabi and white indigenous carers

provided higher levels of support to the older person than the Gujarati group (n=31, 62%; n=27, 54%; n=14, 28% respectively, and see Table 7.5). It is therefore not unreasonable to suggest that the provision of higher levels of care is linked to emotional health and caring as well as perceived morale. Clearly, there is some scope here for positive intervention by health and social care professionals to improve services; if not to lower the level of care carers need to provide, then to improve carers' emotional health and thereby their morale. Hence, some facets of Weiss's typology on relationships (1969), which addresses emotional and cognitive aspects rather than social roles employed are relevant to how service providers can support informal carers (see Chapter 2, section 2.4). Findings showed that Punjabi carers in particular (n=44, 88%, see Chapter 8, section 8.3.2.2) expressed an interest in carer self-help/support groups which encourage 'social integration', and which offer social as well as emotional support (Twigg *et al.*, 1990; Tinker *et al.*, 1994).

The results from this study also showed that many carers were in contact with their GP, and the Punjabi carers in particular also expressed a lot of trust in their GP (see Chapter 8, section 8.3.2.1). Hence, 'reassurance of worth' can be easily achieved by carers through service providers, such as the GP expressing recognition of carers' contribution (e.g. Lewis and Meredith, 1988). Clearly, such an acknowledgement, regularly given, may help to improve perceived morale in heavily involved carers and lessen the perception that their emotional health was suffering as a result of caring. Finally, almost a half of all carers reported feeling totally responsible for care provision to the older person (n=66, 44%, see Table 7.15). When asked how this made them feel (see Q. 59, Appendix 1) the findings showed that carers felt unhappy (n=18, 27%), isolated (n=17, 26%), vulnerable (n=10, 15%), depressed (n=10, 15%), unable to share their feelings (n=8, 12%), and inadequate (n=3, 4%). Hence, 'guidance', such as in the form of counselling (e.g. Richardson *et al.*, 1989), may help to improve emotional health in caring and levels of perceived morale.

The discussion on perceived morale in carers has described some of the differences in the three cultural groups. Most carers reported medium levels of morale ( $n=85$ , 57%, see Table 7.7), which can be considered quite encouraging in terms of general life satisfaction and caring. Nonetheless, as indicated, there is room for improvement, particularly in the Punjabi and white indigenous carer groups. More positive interventions by health and social care service providers can help to achieve the perception of even higher levels of morale. Given that perceived morale is significantly associated with the experience of stress (see Table 8.1), stress in the carers researched is the next issue to be discussed.

### **9.3.2 Stress as Experienced by the Three Carer Groups**

As shown by the results of the present study, the majority of carers in this research perceived that they suffered from stress (see Chapter 7, section 7.5). In terms of cultural differences, the Punjabi group were not only seen to perceive the most stress, they also reported significantly higher levels of stress than either the Gujarati or white indigenous carer groups. In order to find explanations for carer stress there is a need to look at possible explanations for stress. The literature defines two types of stressors carers are exposed to (Pearlin *et al.*, 1990). These comprise primary stressors such as the number and nature of caring activities, and secondary stressors, which concern intra/interpersonal and social/cultural aspects of care (see Chapter 7, section 7.6). The interaction between components are crucial in the understanding of the relationship, if any, between not only what carers do, but also how the different carers in the present study perceived their situation and experience stress. How primary stressors have impacted on the carers researched will be discussed first.

#### **9.3.2.1 Primary Stressors and the Three Groups of Carers**

The findings from the present study support the previous literature available. They have shown that caring tasks carried out by Asian carers in supporting others are not dissimilar to

those of white carers (McCalman, 1990). It is fair to say that higher levels of physical activity in caring alongside other responsibilities may influence the experience of stress in any carer. Findings from the present study showed that there was a significant association between the giving of high levels of support and the experience of stress (see Table 7.13). The group of carers who provided the highest levels of care were also the group who reported significantly higher levels of stress, namely the Punjabi carer group. The Gujarati group of carers provided the lowest level of support to the older person from the same range of tasks and reported the lowest level of stress. Although other variables such as the perceived emotional health of the carer may have contributed to these results, it does appear that the more carers feel they have to do, the more they feel stressed and the more they feel responsible for care provision. Indeed findings showed there was a significant association between feeling fully responsible for care provision and stress, and a significant association between perceived sole responsibility for care and ethnicity (see Tables 7.14 and 7.15).

Both the Punjabi and white indigenous carer groups, who gave significantly higher levels of care than the Gujarati group, also felt more responsible for that care. This factor was described by Punjabi female carers in particular, who related that their experience of stress was brought about by a combination of pressures, such as too much to do in their daily lives as well as being fully responsible for the provision of care. Interestingly though, fewer disability problems were reported in older Punjabi people than for Gujarati or white indigenous older people, which could be expected to result in a lower level of care (see Table 6.8). One possible explanation for this might be that the level of care given depended upon the nature of tasks carers needed to carry out. For example, carers who gave some form of practical care such as keeping the older person company, or helping with meals etc., would not necessarily have needed to get involved with the giving of physical or personal care. Conversely, those carers who did need to help with the giving of physical or personal care were also more likely to have been involved with the whole range of caring activities

(e.g. Parker and Lawton, 1994). Hence, at this stage of the chapter it is interesting to evaluate the caring tasks performed by the carers researched.

Almost all the carers in this study provided help with practical tasks (n=147, 98%, see Chapter 7, section 7.6.3). This can therefore be considered more of a universal task than one that is culture specific and also one that is not essentially related to co-residency. Practical tasks included help with the shopping, preparing meals, laundry, giving medicines etc. Carers reported the most problems with the provision of medical help, which unlike other aspects of practical care was significantly related to co-residency (see Table 6.14). As in other studies on caring, this task can be worrying for carers (Twigg and Atkin, 1994). It has already been established that considerably more Gujarati and Punjabi than white indigenous carers co-resided. Naturally, a lack of proper guidance and instruction, such as in the safe use of equipment and drugs, has potentially serious consequences for all carers. Surprisingly only eleven carers in the present research reported that they had received sufficient instruction and training for their caring role (see Q. 12, Appendix 1). However, the situation may be worsened for older Gujarati and particularly Punjabi carers who may find it difficult to obtain the information they need and can understand (e.g. Bowling, 1990; Donaldson and Johnson, 1990). Previous research has also shown this factor to have great implications for the understanding of health information (Leisten and Richardson, 1996, and see Chapter 3, section 3.5.1). Uncertainty in one's ability to give safe and effective medical help can only add to the possibility of carer stress. Not only was this was mentioned by the carers in this study (see Chapter 7, section 7.6.3), it was also found that the provision of medical help was highly associated with perceived stress (see Table 7.19). Clearly, health care providers need to ensure that carers fully understand what they are doing when giving medical help. Therefore, in order to improve on carers' experience of stress, either carers must be provided with comprehensive instruction and guidance, or certain tasks will need to become the responsibility of health care professionals and not that of the carer.

Another area that was reported as a problem in the provision of practical care was that of role reversal. This was true for carers in all of the cultural groups researched, although role reversal was shown to cause particular problems in both the Punjabi and white indigenous carer groups (see Chapter 7, section 7.6.3). In terms of gender differences, as found in other work (Zarit *et al.*, 1986), male carers found it more difficult to assume responsibility for some domestic tasks such as cooking, whereas female carers found it difficult to take on the more traditional male role such as dealing with financial matters. Previously gender specific roles, particularly between spouse carers, do therefore appear to be a problem once the need for care arises. Again, this is one aspect of care around which intervention policies could be geared.

One final aspect of practical care provided by carers worth discussing concerns that of supervision. Again, the majority of carers were involved with this form of care, and again this was not related to co-residency. Most supervision given by the carers researched was to ensure the safety of the older person. However, as pointed out, supervision implicitly means some form of control over another person, thereby denying autonomy, and whereby independence in an older person may be eroded (Buchanan and Middleton, 1994, and see Chapter 7, section 7.6.4.). This factor can be considered to be at the heart of 'community care' in that it is about giving people choice and independence. On the other hand, in relation to older people needing care because of increasing frailty, it is not an area of care provision for which there are any easy solutions.

As expected, fewer carers were involved in the provision of physical care than practical care (n=101, 67%; n=147, 98% respectively, see Chapter 7, section 7.6.2). Nevertheless, this finding indicates that helping an older person up and down stairs, getting in and out of chairs etc. is a common need of older people. Differences between the groups showed that, unlike the provision of personal care, the number of carers giving physical care was more similar in

the Punjabi and white indigenous carer groups. These latter two groups reported to give significantly more physical care than did Gujarati carers (n=35, 70%, n=39, 78%, n=27, 54% respectively). Again, this is an interesting finding given that fewer disability problems were reported for older Punjabi people (see Table 6.8). One explanation for this might be that the majority of Punjabi carers co-resided with the older person (see Table 6.12) and carers might therefore provide physical help automatically. Indeed the findings from this research showed that there was a significant relationship between the giving of physical support and co-residence (see Table 6.14). Perhaps more important, though, was the fact that further exploration of the data showed there was a significant association between the giving of physical care and perceived stress (see Table 7.17).

Findings also revealed that Gujarati and Punjabi carers were giving physical care at a younger age than the white indigenous carers were, and that older Asians were receiving physical care at a younger age than white indigenous older people were. The findings therefore accord with other research as they show that people from minority ethnic groups may age earlier than the rest of the population (McCalman, 1990) and that, when standardised for age, the incidence of disability is higher among the Asian population (George, 1993). As pointed out above, the implications of these findings are that younger Gujarati and Punjabi people are providing physical care to a younger age band of older people, which implies that they will be caring for a longer period than the indigenous population. This clearly indicates a need for adequate and appropriate services for older people and thereby their carers at a much younger age than the present definition of old age (65 years and above).

In terms of the provision of personal care to older people, it was found that just over one half of all carers helped with this particular activity (n=78, 52% and see Tables 6.14 and 7.16). This indicates that helping older people to wash, dress, use the toilet etc. is evidently a

common activity when caring for older people. It may also help to explain the fact that few friends and neighbours take on the responsibility to care for an older person because personal care might be involved. In the present study, none of the eight non-family carers (female) gave intimate personal care to the older person they were caring for, even though all of these were also female. This is exactly in accordance with other work, which shows that also few friends and neighbours of older people take on the responsibility to care for them (Sinclair, 1990).

In terms of cultural differences and the provision of personal care, the findings showed there was a significant association between such care and ethnicity (see Table 7.16). The white indigenous group helped twice as much with personal care as did the Gujarati and Punjabi carer groups. It appears that intimate care to an older person, including one's spouse, was a matter of particular concern to Asian, and in particular female Punjabi carers who, more than any other group, expressed feelings of embarrassment with the necessity to give personal care. The findings therefore suggest that cultural barriers exist in the provision of personal care. Clearly, this has implications for the type of service carers from different cultural groups may need. If cultural barriers exist, for instance in helping an older person to bath or shower, then it is important that these services are not only more available, but also automatically offered. As indicated in Chapter 2 (section 2.3.1) services such as these are diminishing as a result of the grey areas within the health and social service divide (e.g. Robinson, 1991). Hence, there is a clear need for bathing services to be formally delineated as either a social or a health care provision, for which either service needs to accept responsibility.

The findings described thus far demonstrate that primary stressors, as outlined above, may impact on carers' experience of stress. In this study, the Punjabi group of carers, especially the female carers, appeared to be more affected by this type of stressor. They provided

higher levels of care than either the Gujarati or white indigenous carer groups and were therefore exposed to more primary stressors. Nonetheless, equally important to the understanding of the stress process in the carers researched are the secondary stressors such as intra/interpersonal and social/cultural issues. These will now be discussed in turn.

### **9.3.2.2 Secondary Stressors and the Three Groups of Carers**

Intrapersonal factors such as self-doubt in the ability to provide care have been examined in this thesis (see Chapter 4, section 4.2.5). As previously indicated, many of the carers in all three cultural groups expressed concern about the care they provided. Linked to this factor is the amount of information they may receive in order to carry out their role to their own and the older person's satisfaction. Associated findings from this study showed that, although the exact history of the older person's condition and needs were not collected, almost one quarter of the carers (n=34, 23%) perceived they were ill informed regarding the older person's condition (see Q.14, Appendix 1). Carers' complaints included being kept ignorant of the true diagnosis, particularly in relation to mental health issues. Having said that, it would also be true to say that mental illness may be stigmatised in Asian communities (see Chapter 6, section 6.3.2), and therefore carers from these groups would not necessarily seek relevant information. Other complaints came from carers who were not family members. One particular carer looking after her neighbour, who had no family in the area, was actually refused information because she was not a family member. More disturbing was the fact that this carer reported that some service providers were suspicious of her motives to care and treated her like a 'vulture'. In addition, this carer reported that she was unable to obtain services from social service providers such as a home help because she was not a family member. Clearly, if the state want more 'care by the community', they need to educate service providers further as to the rights and needs of carers who are not related to the older person they are caring for.

In addition to the need for actual physical and practical tasks in caring, carers also considered themselves responsible for the older person (n=66, 44%, see Table 7.15). As argued by writers who have researched into caring, this sense of responsibility is at the heart of how carers experience their role (Qureshi and Walker, 1989; Twigg and Atkin, 1994). At this point it is interesting to note how Twigg and Atkin's (1994) first and second models of the carer role (carers seen as a basic resource or regarded as a partner in care) relate to the present research (see Chapter 2, section 2.4). The findings have shown, firstly, that it is the family that provides care to older people (see Tables 6.10 and 6.11). Secondly, it has shown that people care out of duty or love (see Tables 7.1 and 7.2), and as the quotations from the carers have demonstrated, care is also provided out of personal ties and reciprocity (see Chapter 7, section 7.2). Thirdly as pointed out above, over two fifths of carers felt responsible for that care. Twigg and Atkin (1994) argue that because of these factors, carers are basically seen to be taken for granted by social care agencies. However, when the carers in the present study were asked how they viewed their relationship with professionals only just over one quarter reported they felt taken for granted (n=39, 26%, see Q. 33, Appendix 1). Given that past research has argued that older people and their carers from minority groups are considered invisible (Baxter, 1988; Franklyn, 1992; Patel, 1994; Walker and Ahmed, 1994), one might have expected that it would be mostly the Gujarati and Punjabi groups who felt taken for granted by professionals. Surprisingly, however, the findings showed that the majority who felt taken for granted were the white indigenous carers (n=22, 56%), as opposed to the Gujarati carers (n=6, 15%) and the Punjabi group (n=11, 28%). One explanation for this could be that, when asked about whether carers felt prepared to care (see Q.14, Appendix 1), especially for parents/parents-in-law, a significant majority of Asian carers reported that they did (see Table 7.20).

One could look at this finding in two ways. Asian carers may have perceived that they would be 'caring for their own' and therefore would not expect much help from health and

social service professionals. However, there may also be some truth to the argument that Asians do not challenge professionals and/or do not like 'handouts' (see Chapter 3, sections 3.5.1 and 3.6). Nonetheless, Asian carers need, firstly, to be fully aware of available services before they can perceive whether or not they are being taken for granted. Therefore, if carers perceive that they will need to provide the bulk of care, particularly to an older relative such as a parent, when the need for care arises, they rightly or wrongly feel less taken for granted by social care professionals.

The findings from this study also showed that, in terms of carers feeling they were partners in care, as in Twigg and Atkin's second model, the majority of carers reported they felt they were indeed working together with professionals in order to care for the older person (n=89, 59%). Although this model does have great appeal to all those involved in the caring continuum, it nevertheless tends to ignore the possibility of power differentials in the caring relationship. This does not only relate to formal and informal care, but also to the relationship between the older person requiring care and their informal carer (e.g. Matthews, 1979; Fisher, 1986, and see Chapter 4, section 4.2.5). The findings from the present research have demonstrated the conflict that can arise, particularly between carers and their parents and parents-in-law (see Chapter 7, section 7.6.4).

In relation to Asian carers, the findings also accord with previous literature, which has highlighted the possible conflict in households between daughters-in-law and mothers-in-law (Ahmad, 1996 and see Chapter 3, section 3.3.3). Reports from carers taking part in this study where power struggles took place have described how Punjabi female carers (as daughter-in-laws) appeared to be affected by control of the elder within the family over them. As exhibited in Tables 6.10 and 6.11, more female Punjabi carers than any other cultural group were responsible for the care of their in-laws, and as indicated earlier, female Punjabi carers also reported the highest stress levels. However, many female Gujarati carers

also cared for their in-laws. One explanation here may be that female Gujarati carers may have found it socially inappropriate to express negative comments regarding the care they gave to in-laws. Nevertheless, the objective measures of stress showed that the female Gujarati group also reported significantly lower levels of stress (see Table 7.12). Clearly, other variables may have contributed to these findings, but the one constant theme discerned from the interview material was the general dissatisfaction with caring expressed by female Punjabi carers, particularly when caring for a mother-in-law. As indicated above, the availability of culturally sensitive counselling and support groups, especially for Punjabi females, may be of some value.

The findings also showed more specific cultural issues of concern. Both Gujarati and Punjabi carer groups expressed difficulties in obtaining suitable food both in hospitals and in the community. The correct diet is a cultural and religious imperative to many Gujarati and Punjabi families and it forms a major part in their daily lifestyle. Clearly, the lack of appropriate food to older people and their carers is not a reflection of good practice, and again this is an area that calls for more proactive intervention by service providers.

So far, the findings have shown some general similarities and differences between the three cultural groups. It is difficult to say exactly what constitutes a source of stress in individual carers as there are obviously varied reasons. However, it is hoped that the findings generated by this research may give the reader some insight into the stress process as experienced in the different situations and lifestyles of separate cultural communities. It is now important to examine what is known about factors which mediate the relationship, between what carers do, their situations and their perceived experience of stress. The question is, why do some carers cope and others not, and how can carers be helped to adapt to their role more successfully? Findings from the present study that relate to hypothesis 3 on carers' coping abilities and internal and external coping mechanisms are discussed next.

#### **9.4 Internal and External Coping Strategies Employed by Carers**

At this stage, it is helpful to remind the reader of how the different carer groups perceived their coping ability. In Chapter 8 (section 8.2.1) the statistically significant coping scores were detailed. Here it was exhibited that the white indigenous and Gujarati carer groups reported much higher coping ability levels than did Punjabi carers. In many ways, this was an expected outcome as Punjabi carers reported relatively lower levels of perceived morale, and significantly higher levels of perceived stress than the other two groups. It was also demonstrated that morale, stress and coping were all significantly associated with one another (see Table 8.1). Nevertheless, in order to gain an insight into why the Gujarati and white indigenous groups appear to have coped better than Punjabi carers, it is necessary firstly to appraise carers' internal coping mechanisms.

##### **9.4.1 Internal Coping Mechanisms Employed by Carers**

Coping strategies basically consist of active and avoidance processes. Previous research has shown that active coping mechanisms are considered more effective for psychological adjustment than avoidance techniques (Billings and Moos, 1981; Matson, 1994). Findings from the present study showed that the carers as a whole used more active coping strategies than avoidance mechanisms ( $n=431$ , 65%;  $n=234$ , 35% respectively, and see Table 8.5). The findings also showed that the white indigenous group not only used more active coping mechanisms (see Table 8.5), but they also employed considerably more of a range of active processes in their caring role than either Gujarati or Punjabi carers (see Table 8.6). Also, it was the Punjabi group who used the least active coping mechanisms. In terms of the different active strategies employed, white indigenous carers used significantly more ways to overcome problems, avoid worry, use positive thought and perform active planning than the Gujarati and Punjabi carer groups. These findings indicate that there are differences in the way people from different cultures cope in given situations. This also clearly demonstrates the more individualistic and assertive action of the white indigenous carer

group as opposed to Gujarati and Punjabi carers (see Chapter 8, section 8.2.2). Given that active strategies are considered the more positive coping technique, there is clearly room here for health and social care workers to help Asian carers employ more active coping strategies.

Although all three cultural groups also reported using different avoidance strategies in their role as a carer, the number used was much lower than the number of active strategies employed (see Table 8.5). Unlike with the use of active coping strategies, none of the carers used the whole range of techniques listed (see Table 8.8). Gujarati carers used the least number of avoidance coping mechanisms. Some cultural differences were evidenced in the use of different avoidance coping techniques. Significantly more white indigenous carers avoided problems by keeping busy, and significantly more white indigenous carers ate, drank and smoked more than the Gujarati and Punjabi carer groups. However, significantly more Punjabi carers than white indigenous, and particularly Gujarati carers, avoided problems by ignoring them (see Table 8.9). One explanation for this may be that not only did Punjabi carers provide higher levels of care, thus perhaps having to ignore some problems, but they also experienced more communication difficulties with formal service providers and were therefore unable to tackle problems effectively. Clearly, making practical support to carers a high priority would reduce the need for some carers to feel they should ignore the situation.

Looking at the use of active and avoidance coping strategies together, the findings show that the Gujarati and white indigenous carers employed two-thirds of active coping mechanisms ( $n=124$ , 69%,  $n=198$ , 68% respectively) and one third avoidance techniques ( $n=56$ , 31%,  $n=93$ , 32% respectively). However, the Punjabi group used more similar proportions of active and avoidance techniques ( $n=109$ , 56%,  $n=85$ , 44%, see Table 8.5). It does therefore appear that the Punjabi group, in particular, might find some help to increase the use of more

active coping strategies and decrease the use of avoidance coping techniques helpful. This may then help this group to improve their perceived coping abilities overall.

Against this background, the final part of this section turns to the external coping strategies. The literature points out that the major factor believed to help carers to cope are time off from caring, services received, and satisfaction with help from others in their informal network (Parker, 1992). This section therefore begins by discussing time off from caring in the three cultural groups of carers researched.

#### **9.4.2 Carers and Time off from Caring**

As outlined above, time off from caring is considered a major factor in helping carers to cope. The findings demonstrated that there was a significant association between residency and time off from caring (see Table 8.10). As expected, carers who co-resided reported significantly fewer regular breaks. Almost one half reported spending over 100 hours on caring activities per week (see Table 6.16). Clearly, many of these carers should be offered the opportunity of a break, and this is an area that has recently gained some publicity and which the Government intends to address in its new Caring for Carers: A National Strategy. In addition, if service providers arrange time off from caring specifically to help carers, then this would demonstrate that carers are indeed regarded as co-clients as per Twigg and Atkin's third model in the caring continuum (see Chapter 2, section 2.4). It would also show that service providers were acting proactively in ensuring the rights of heavily involved carers according to the Carers (Recognition and Services) Act, 1995.

In terms of cultural differences and length of break, the findings from this study showed that, of those who did have a break, significantly more white indigenous carers received a longer break from their caring responsibilities than either Gujarati or Punjabi carers (n=18, 49%; n=4, 13%; n=1, 3%; and see Table 8.11). The interview material showed that over a

half of white indigenous carers who enjoyed a longer break received respite care (n=11, 61%), but only one Gujarati and one Punjabi were in receipt of this service. As outlined in Chapter 3 (section 3.6), respite services were considered to be the least known community service to carers from Asian communities. Although the evidence collected does not show whether Gujarati and Punjabi carers were unaware of this particular service or did not use it as it was not culturally sensitive, the findings indicate that there is a dire need for culturally appropriate respite places for older Gujarati and Punjabi people. At present, it does appear that the Government intends to allocate £140 million for respite care for carers (Hibbs, 1999). However, it does not specify whether this money will also ensure culturally specific respite services, or whether it is just intended for mainstream respite provision.

Although additional data showed that most white indigenous and Gujarati older people and their carers had access to day care services, either formally organised or provided more on a community basis, Punjabi older people and their carers did not. The majority in this latter group appeared not to be able to access a culturally appropriate group (other than their own local community organisation, which was more for social activities). Many carers in this latter group, in particular older spouse carers, spoke of the sense of loneliness and social isolation they endured. Younger carers supporting an older person spoke of the confinement at home, unable to leave the older person for any length of time (see Chapter 8, section 8.3.1). Again, respite care in the form of culturally sensitive day care provision would be of enormous help to many carers.

#### **9.4.3 Support to Carers from Formal Service Providers**

The State has made it clear that it is unable fully to sustain the costs of care for the increasing numbers of frail older people (see Chapter 2, sections 2.2 and 2.3). Hence, 'care in the community must increasingly mean care by the community' (Growing Older, Cmnd. 8173, 1981). Writers argue that in effect this means that the family is seen more as a

substitute for government organised services (Bamford, 1990), and especially Asian families who, it is believed, 'care for their own' (Patel, 1994; Walker and Ahmad, 1994, and see Chapter 3, section 3.5.1). Therefore, a poor uptake of services can be justified as a lack of need. However, as outlined in Chapter 3 (section 3.1), previous research has argued that Asians do not receive appropriate, accessible and adequate services to meet their needs. In the context of home-based community care and regular visits from health and social care agencies, the findings from this study are not in full accord with this view. The data collected showed that Gujarati and particularly Punjabi older people had more contact with health and social care professionals than older white indigenous people (see Table 8.12). However, where the findings from this research do agree more is that the needs of older Asian people and their carers appear to be slotted into mainstream service provision. Instances of inappropriate services, such as insensitive and inadequate home-help services and unsuitable meals-on-wheels, were described in Chapter 8 (section 8.3.2.1).

In Chapter 3 (section 3.6) it was highlighted that the Asian community subscribed well to GP services and the findings from the present study are in accordance with this as there was a significant association between visits from the doctor and ethnicity (see Table 8.13). However, research had also shown that GPs do not liaise much with other social and health services and this results in low rates of referral to other formal agencies (Wilson, 1992b). Results from this study tend to agree with this view. It was shown that older Punjabi people in particular were in more contact with the doctor than either Gujarati or white indigenous older people, and also reported the provision of more basic services (see Chapter 8, section 8.3.2.1).

Conversely, the findings also showed that white indigenous and Gujarati older people and their carers appeared to be in more contact with specialist services than Punjabi older people and their carers. This was despite the fact that, as outlined earlier, Punjabi carers were more

heavily involved in caring. This suggests that referrals from the GP to other service agencies might appear to be more accessible for some cultural groups. Obviously, other variables such as a prior knowledge of what may be available from formal service providers with the help of a community/link worker may have contributed to these results. It does appear that this factor may help to explain why the Gujarati community is better able to communicate with health and social care agencies than the Punjabi population. It may also help to account for the significantly lower level of satisfaction with formal services reported by the Punjabi carer group. Naturally, the ability easily to access a varied range of formal service provisions indicates a propensity to cope better with the caring role. Indeed, in this study, the majority of Punjabi speaking carers reported that one coping ability they preferred to use in their caring role was to turn to professionals such as the GP for help and advice when needed (see Chapter 8, section 8.3.2.1, and see Qs. 70 and 71, Appendix 1). Often being unable to communicate satisfactorily meant that many carers' needs were left unmet. It is perhaps not surprising that this group of carers who provided higher levels of care, yet who were unable effectively to use their expressed preferred coping mechanism, were the group who reported significantly lower coping abilities (see Table 8.3).

#### **9.4.4 Help to Carers from Their Informal Network**

The findings have shown that almost one half of the carers felt solely responsible for care provision to the older person (n=66, 44%, see Table 7.15). This clearly indicates that many carers did not perceive much help in their caring role from other family, friends and neighbours around them, who one might have assumed would be on hand to help. However, only a minority of carers reported no help from their informal network (n=16, 5%, see Table 8.16). As expected, many of the carers in this study reported the receipt of most help from their family (n=134, 46%). However, almost one quarter of friends and neighbours (n=69, 24%; n=71, 24% respectively) gave any instrumental support to carers. This indicates that not only do friends and neighbours not take on the role of main carer of an older person,

they also do not tend to automatically provide much concrete help to carers themselves. Nonetheless, carers also perceived that friends and neighbours would help more if asked.

In relation to cultural differences, the Punjabi group of carers reported that they received more help than either of the other two groups (see Table 8.16). However, they were significantly less happy with any help received from family, friends and neighbours than were the Gujarati or white indigenous carer groups. This finding accords with other work, which argues that, when stressed, carers are more likely to perceive any help they receive negatively, regardless of the level of help received (Braithwaite, 1990).

As indicated, the Punjabi carer group not only reported significantly higher levels of stress, they also reported significantly lower coping abilities than the other two groups. It does therefore appear that in order for functional help with caring to be an influencing factor in helping carers to cope, carers must first be in a position to feel satisfaction with the help received from others. In addition, the findings demonstrated that it is not necessarily the amount of help carers receive that helps carers to cope, rather it is satisfaction with that help that may help to enhance coping abilities and reduce stress. This factor was more pronounced in the Gujarati carer group (the least stressed) where the information revealed by carers showed that for this group, friends and neighbours were regarded more as a community network rather than viewed separately for different social activities.

Female white indigenous carers in particular, however, reported using friends and neighbours differently and on a more emotional level, such as someone to confide in. This factor therefore suggests that some components in social support may be more important to individual carers than others and that quantity of support does not necessarily outweigh quality of support.

## **9.5 Conclusion**

This chapter has detailed and described the main and associated findings concerning the situation and experience of caring in different cultural groups. It has clearly demonstrated that care in the community is not shared in the community. Responsibility for care of an older person generally falls on the shoulders of the family and, as the findings have shown, the locus of care tends to be with one family member who is also more likely to be female. Findings from this study have also indicated a clear link between objective and subjective burden. They have done so by demonstrating that carers who provided higher levels of care perceived significantly higher levels of stress. Hence, the results gathered from this research have implied that many carers incur financial, social and psychological costs, which are only partly met by existing services. Clearly, if service providers wish to make practical support to carers a high priority, then interventions need to be more proactively targeted towards carers if they are to continue in their caring role.

In terms of variations between the three cultural groups, the findings support hypotheses 2 and 3. Results have shown that there is a significant difference between the three groups and their experience of stress, and internal and external coping abilities. Given previous research, one would have thought that these differences existed more between the Asian and white indigenous carer groups. However, the findings have demonstrated some distinct and significant differences between the Gujarati and Punjabi carer groups. Punjabi carers appear to experience more stress in their caring role, do less well in accessing formal services and report lower coping abilities than Gujarati carers. Explanations for this may include the fact that the Punjabi carers in this research were providing higher levels of care and reported a lesser ability to communicate with formal service providers than the Gujarati carer group.

Given the above findings, it is clear that, overall, carers are not yet at the stage where they are seen as co-workers in the caring continuum. In particular, Punjabi carers appear to be in

a more negative position regarding their role as a carer. Therefore, it is vital not only to enquire more into cultural differences in carers, but also to ask how better to support carers in general and especially the more marginalised minority ethnic communities. The following chapter endeavours to suggest how this might be achieved.

## CHAPTER TEN

### RECOMMENDATIONS AND CONCLUSIONS

#### 10.1 Introduction

This research has attempted to provide a better understanding of caregiving in different ethnic communities. It has approached this by examining the differences and similarities between specific cultural groups with the aspiration to derive wisdom that is applicable to all. Through interviews both quantitative and qualitative material was collected, analysed and interpreted relating to carers from two South Asian communities and a white indigenous group. The focus on Gujarati and Punjabi groups was intended to demonstrate the diversity in circumstances and experiences between two cultural groups who are often classified as one in the 'South Asian' category. Additionally the research arose from the apparent paucity of published information on individual carers from different cultural backgrounds even though informal carers are of special importance in community care initiatives for older people.

This study has made it clear that the family is, as it always has been, the main source of support given to older people. By providing this care, and in accordance with other work, the findings have shown that informal carers in general were exposed to, and incurred, financial, social, physical and psychological costs (e.g. Cantor, 1983; Parker, G., 1990; Twigg, 1992; Thoits, 1995; McKee *et al.*, 1997). Hence, carers in all cultural groups have universal needs, which can be met by the objectives outlined in the White paper 'Caring for People' (Cmnd. 849; 1989). This chapter, therefore, sets out to, firstly, raise a platform for all carers of older people.

Secondly, it is hoped that recommendations arising from this study will be used to help formal service agencies to provide a user sensitive service to all carers, no matter what their cultural background. Care has been taken to ensure that any recommendations made will be both realistic and cost effective, in both the short and the long term, and these basically involve more sensitive organisational and management procedures. Finally, suggestions for future research on carers from different cultural groups are made. Having provided the findings in Chapter Nine, this next section (section 10.2) presents a brief summary of the main universal findings generated by the present study with recommendations that relate to all carers. It then goes on to outline some of the main differences found to exist between the three cultural groups, and again makes some suggestions designed to improve the caring experience in carers from Asian communities (section 10.3).

## **10.2 Universal Findings and Recommendations to Help All Carers**

One of the main objectives outlined in 'Caring for People' (Cmnd. 849, 1989) was to make practical support to carers a high priority. However, many carers merely see themselves as wives, husbands, daughters, sons etc., and therefore remain invisible to many service providers. Given that information both to and about older people and their carers is vital if service providers are to be able to support them, these first recommendations are concerned with the provision and dissemination of information to all cultural groups:

### **10.2.1 Information**

Both previous literature (Hospital Plan for England and Wales, Cmnd. 1604, 1962) and the findings from the present study have shown that the GP is the first point of contact for most people. Hence, GPs are in a position to pass on essential information to others. Therefore, the first recommendation is that:

- Information from GPs could be used to develop a local and national register of carers listing the characteristics of carers and those of older people so that service providers are aware of individual needs and can thus meet their objectives.

Not only is information regarding older people and their carers important in the caring continuum, information to them is also essential if they are to be able to continue caring (e.g. Richardson et al., 1989), particularly if they are to be seen as partners in care (Twigg and Atkin, 1994). The findings from the present study showed that the carers, as a whole, perceived stress. Unmet needs may impact on carers' experience of stress, which may affect their ability to continue providing care. One main finding which came to light during the interview process was that some carers were unaware of the true condition and prognosis of the older person they were caring for. Clearly, this affects carers' ability to cope and deliver safe and effective care. In addition, many carers were unaware of the varied services and benefits available to them and the older people for whom they were caring. Health, community, social services and voluntary agencies have an important part to play in providing not only relevant local, but also national information. Therefore:

- All carers need to be given as much information as is known about the older person in their care by health and social care professionals such as the GP. Where necessary this could be presented in the appropriate language or given via an interpreter.
- Basic information, such as local and national addresses and whom to contact regarding the different organisations and general benefits available to carers need to be available as a small package in different language styles. These

could not only be displayed in all health and social care and voluntary organisations, but handed to older people and their carers by the GP, community nurse, health visitor, on hospital discharge etc..

- It is also suggested that the local authority make available funds to arrange for all local voluntary agencies, social and community service departments to be listed in a booklet and/or presented in different languages in audio/video form. This should include their area of specialism and a designated name and address to enable carers to make contact for a particular problem.

Some carers reported the inability of some health and social care professionals to refer them to other appropriate formal agencies. It appears that many were unsure and uncertain of whom to contact and how to go about it. Therefore it is suggested that:

- Information regarding other health and social care services could be made available to other departments and agencies so that carers can be appropriately referred. This would also need to be updated on a regular basis. In addition funding for telephone information helplines and 24-hour answering machines to take messages should be considered.

### **10.2.2 Health and Social Services**

The majority of carers in this study reported they were coping well (n=89, 59%). Nevertheless, many of the carers also reported a need for further aids and equipment to help them cope better, which may be available from health and social service departments. Of the aids carers expressed a need for, very few appeared to be readily available. Under the Carers (Recognition and Services) Act, 1995, heavily involved carers have a formal right to an

assessment of their particular needs. This includes the provision of necessary equipment to help them care. Hence, these next few recommendations apply to health and social services:

- Community care service departments need to target carers and ensure they are equipped to safely and effectively carry out any necessary procedure. When providing vital aids, relevant training and guidance in using equipment needs to be given automatically.
- Local authorities could set aside specific funding to allow for basic adaptations in the homes of older people and in those residing with their carer.

In Chapter 7, it was shown that most of the carers reported that their emotional health had significantly suffered as a result of caring. In addition, the findings demonstrated that many carers feel vulnerable and totally responsible for care provision to the older person. Hence:

- Emotional support, such as counselling and/or assertiveness training in different languages or via an interpreter, needs to be readily available and routinely offered. The availability of trained counsellors to support carers and enhance their coping abilities may be as important as the provision of practical help in caring for an older person in the community.
- Carers need to be made a priority in practice as well as in theory. A named person within each community and social care department could assume the responsibility for giving advice, as well as dealing with complaints made by carers. Any problems should be recorded and analysed regularly. This would enable any particular weak areas within local service agencies to be addressed swiftly and efficiently.

A minimal number of the carers received respite services to give them a break from continuous care responsibilities. The phasing out of respite beds by hospital trusts has led to an underfunding of this essential service and has created an increase in unmet needs. Thus, heavily involved carers are more open to physical and emotional stress and a possible breakdown of their health. Regular time off from caring has been shown to be an important factor in helping carers to cope (Parker, 1992). Therefore:

- The recent promise of grants worth more than £140 million in the forthcoming document 'Caring about Carers': A National Strategy for Carers (DOH, 1999), which is meant to enable carers to take a break, could be used to establish the provision of culturally appropriate respite places in private organisations. Innovative schemes, such as temporary care in a volunteer's home, could also be instigated and monitored.

The findings and following recommendations above apply to all carers of older people whatever their cultural background. In order for carers to care effectively, both information about, and to carers, need to be readily available. Carers also need appropriate aids and the opportunity of a break from caring. As important as practical support is the availability of emotional support.

The findings from the present study also highlighted some significant differences between the three cultural groups. It was expected that these differences would exist more between the white indigenous control group and the Gujarati and Punjabi communities. However, the findings showed that there were more differences between the Gujarati and Punjabi carers than between white and Asian carers. This very factor demonstrates the need for policy planners and service providers to realise that when they talk about minority communities

having particular care needs (Caring for People, Cmnd. 849, 1989), that different cultural groups experience the caring situation in very different ways. Hence, the next section of this chapter presents these differences alongside recommendations to improve the experience of caring for carers from Gujarati and particularly Punjabi communities.

### **10.3 Cultural Differences**

The findings from this study consistently showed specific differences in the experience of caring in the three groups of carers. Most of these differences existed between the Gujarati and Punjabi carer groups; nevertheless, the findings also showed some similarities in the caring experiences of the white indigenous and Punjabi carers. Given that differences in Asian carer groups were found, the present study highlighted the need for more in-depth classification of ethnicity. Hence, appropriate ethnic monitoring is required.

#### **10.3.1 Ethnic Monitoring**

In order for the local authority to identify the composition, location and needs of Asian and other minority groups it is suggested that:

- Ethnic monitoring needs to be based on cultural background rather than based on an individual's race. For example, monitoring could be according to Gujarati, Punjabi etc. so that their community language can be identified and acted upon. This form of local and national ethnic monitoring will enable the relevant authorities to employ staff who are able to communicate with the different cultural groups of older people and their carers. It will further enable health and social care agencies to review and adapt available services accordingly.

### **10.3.2 Formal Service Provision**

One of the most important factors, which surfaced through this research, was that Asian carers were providing care to significantly younger age band of older people at a significantly younger age than the white indigenous population. This implies that Asian carers will be caring for a longer period of time than white indigenous carers, to whom mainstream services are normally directed. Clearly, this difference in age profiles requires some recognition in the community care system. In order for health and social services to provide an equitable service to carers of older people in younger age groups, it is suggested that:

- Health and social service providers do not delineate services to older people according to age only (i.e. 65 years and above). Community care planners and service providers need to take into account that Asians may age earlier than the white population. Therefore, services such as day care for older people need to be available at a younger age.

To ensure that services are appropriate, equitable and accessible to the needs of particular local minority ethnic populations and the individuals within those groups, racial equality principles should be reflected in a number of areas:

- On an individual level, this needs to be incorporated into the assessment and planning processes in care management of older people and their carers. For example, by ensuring that Asian carers are automatically offered culturally sensitive community services, such as appropriate meals-on-wheels. On a wider level, this would involve purchasing spot contracts (a one-off purchase) where necessary and ensuring that service specifications actually meet different needs.

The findings from the present study highlighted the fact that a majority of Punjabi carers relied on their own local voluntary group for social support etc., yet this group of carers was also significantly less satisfied with the help they received from family, friends and neighbours. Hence:

- There is an urgent need for the wider availability of culturally sensitive organisations Punjabi carers can contact for help, advice, information etc. Both statutory and voluntary agencies need to ensure that they consult the different minority ethnic communities to elicit opinions on the needs of the different groups. It is also suggested that they visit community centres to promote and explain what they do and how older people and their carers can access further information.

Carers from both Gujarati and Punjabi communities reported occasional insensitivity to their way of life, such as the complaints about the smell of Indian food by home-helps. In order to meet the particular needs of the different communities, such as culturally appropriate services, there is a need for:

- Training of health, social and voluntary staff in the different cultural and religious belief systems of local minority ethnic communities, which would enable the development of a more user sensitive service. In addition, formal service care workers need to be made aware of legal obligations outlined in the Race Relations Act, 1976.

The lack of culturally appropriate services and facilities within health, social and voluntary care found in previous research (e.g. Ely and Denney, 1989) has also been a feature of this

study. For example, the complaint by many of the carers that formal service food provision was incompatible with religious and cultural imperatives. There is therefore an urgent need for:

- The availability and offering of Indian vegetarian and Halal menus. In addition, older people and their carers need the assurance that food has been prepared according to cultural and religious imperatives, such as not cooked in pans previously used for meat.

A further concern voiced by female Gujarati and Punjabi carers in particular, was the preference for the availability of health care staff of the same gender. As the findings showed, significantly fewer Gujarati and Punjabi carers than white indigenous carers gave help with personal care. Thus:

- Mainstream services such as hospital care, GP services and community-based provision could be orientated towards both gender and culture. For example, the availability of more female Gujarati and Punjabi speaking doctors when intimate consultations are necessary, and the availability of male and female health care professionals in the community who would be able to help with bathing etc..

In addition to services actually provided to carers, results showed that significantly fewer Gujarati and Punjabi carers received a longer break (of two days or more) from their caring responsibilities. There is therefore a clear need for the availability of:

- Culturally appropriate provision of respite care. As with the issues concerning all older people and their carers, a project to promote the delivery of care, such

as day and respite care, in the homes of individuals of the same culture could be instigated and monitored.

In Chapter 8 (section 8.3.2.3) it was shown that some of the Asian carers were concerned about the type of accommodation provided to their elders. Hence, this research indicated the need for culturally appropriate, authority funded accommodation for older people. The Gharana Housing Association has done much to enable older people from a Gujarati speaking background to live more independent lives. However, Punjabi carers reported there were no such facility for older Punjabi people.

- A severe lack in the provision of Punjabi speaking, warden controlled accommodation for older people has been noted. Therefore, there is an urgent need for such a facility.

### **10.3.3 Communication**

Gujarati carers reported significantly fewer communication problems with formal service providers than Punjabis. They also reported contact with a community/link worker who was able to understand their language and their way of life. For Gujaratis, this service was seen as one of the most beneficial. Conversely, Punjabi carers were more in contact with basic service providers, especially the GP. Although, for Punjabi carers, the GP was seen as very helpful, overall they were significantly less happy with available formal service provision. Findings therefore suggest that the Punjabi speaking community in particular would benefit from a wider availability of Punjabi speaking health and community care employees.

- Positive action in the employment of staff according to the local cultural make-up of communities would be of immense value to older people and their carers from different cultural backgrounds.

As indicated, language and cultural issues were found to be a dominant theme in concerns expressed by these two groups of carers. The inability to communicate effectively with others in the same language, and from the same culture, was found to be of concern to many older people and their carers. Such barriers particularly affected the members of the Punjabi community. Taking a family member or friend to translate information is not considered satisfactory by many of the respondents. It appears that language-based help, such as the ability to speak in the same language, or the use of a trained and skilled interpreter, would be the preferred means of overcoming communication barriers for older people and their carers. Gender should also be taken into account in the provision of this service. Thus, there is a need for:

- The availability of interpreters both skilled in the different languages, and trained to use appropriate terminology. However, these services should not just be available if asked for, they need to be actively offered to older people and their carers.

Given that many Punjabi carers in particular were limited in their access to and awareness of more specialised service provisions, material presented should focus on certain themes, such as health screening, available services and benefits, and how to access them. This may help to improve this group's perceived level of morale, stress and coping abilities. Hence:

- Health, social and voluntary organisations could present a wider selection of material in different language styles, both printed and in other forms, such as audio and video cassettes, to maximise effective communication.

The results collated in this research have identified factors which may inhibit or encourage coping on the part of those caring for older people. Thus, this study has endeavoured to make

practical and appropriate recommendations for a more sensitive provision of services to carers of older people. Findings have also shown that Asian communities are more heterogeneous than homogeneous. More importantly though, it appears that given the significant age differences in both carers and older people from Gujarati and Punjabi communities, these carers may need to care for longer than the white indigenous population. Hence, it is now also important to make suggestions for research, which may help to improve their situation in the future.

#### **10.4 Future Research**

This study has only touched the surface of caring situations and experiences of carers from different cultural groups. By doing so it has opened up a whole series of questions, such as why did the Asian carers researched report that they cared more out of duty than love. It would be fascinating to delve further into the language of caring in carers from different cultural backgrounds, as this would enable a deeper understanding of the complex interaction in motivations to care and thus how carers view and experience their caring role.

On a more pragmatic level, there are other questions that have policy relevance. For example, why do Punjabi carers have more communication problems with formal service providers than Gujarati carers, when the literature reports that Punjabis migrated to Britain earlier than Gujaratis? How are service planners and providers going to address this problem? Future surveys and research into caring need to specify not only the gender, age, class, ethnicity, etc. of participants; the inclusion of participants' cultural background in demographic characteristics of the sample is important if there is to be a better understanding of the nature of caring in different cultural groups.

As pointed out in Chapter 5, no psychosocial measures concerning stress, coping etc. which had been used on minority ethnic populations were available at the outset of this project.

Future research design into the caring experience needs to develop appropriate objective measurement techniques suitable for cross-cultural application.

As policy planners and providers strive to meet unmet needs of minority ethnic communities in Britain, there is a pressing need for cross-cultural research on caring to examine possible cultural differences. This needs to be able to encompass the appraisal of stressors, coping ability, specific coping strategies and social support systems in moderating the impact of stress. Such research is likely to show that cultural differences affect many aspects of care provision to an older person and thus can be used by planners and service providers to address these differences, rather than base provision on assumptions and inappropriate generalisations about these different groups. One way of achieving this might be by using matched samples (not possible in this study), thereby enabling the employment of path analysis and other inferential statistics to analyse quantifiable data. This would allow for the building of a model concerning the inter-relationship between the various factors and the nature of the relationship between stress and internal and external coping strategies and mechanisms.

Finally, research needs to concentrate more on the positive aspects of caring in order to further extend knowledge regarding carer adaptation so that interventions and policies may be designed to enhance carer well-being.

### **10.5 Conclusion**

The findings generated by the research indicate that the focus on the different cultural groups was well founded. By doing so, the study has contributed to existing literature and current understanding of carers from different cultural groups by exploring their experiences, needs and practical strategies. Caring for older people is often a long-term

commitment and individual caring situations are constantly changing and evolving. Nonetheless, the present study has been able to demonstrate some of the interactions between culture, language, motivations to care, caring activities and thus caring experiences as perceived by individual carers. It was shown that, in addition to some distinct differences in caring between Gujarati, Punjabi and white indigenous carers, there were also some similarities which existed between the different Asian groups and the white indigenous carer group.

Main differences between Asian and white indigenous carers were comprised of the fact that significantly more Asian carers than white indigenous carers co-resided. Asian carers also looked after a wider range of older relatives in the same household than white indigenous carers. In terms of employment, fewer Gujaratis and Punjabis than white indigenous carers were in paid employment. However, one important finding in relation to this research was that Asian carers were providing care to a significantly younger age group of older people at a significantly younger age than white indigenous carers. Asian carers were also significantly less likely to enjoy a longer break from their caring role than white indigenous carers. These two findings alone have implications for the level of service required by Asian carers, if formal care agencies are to make practical support to all carers a high priority.

Main differences between Gujarati and Punjabi carers included the significantly better ability by Gujaratis to communicate with formal service providers, which in turn may have influenced the fact that Gujaratis reported accessing a wider range of facilities than Punjabi carers. Interestingly, there were many similarities between the Punjabi and white indigenous carer groups in terms of providing significantly higher levels of care, perceiving sole responsibility for care, and perceiving that their emotional health had suffered as a result of caring.

In terms of coping there were more similarities between the Gujarati and white indigenous carers. Both groups used proportionately more active and less avoidance coping mechanisms than Punjabi carers and both groups were significantly more satisfied with help from formal and informal sources than Punjabi carers. Owing to this, it is not surprising that overall, Gujarati and white indigenous carers reported higher levels of morale, significantly lower levels of stress and perceived significantly higher coping abilities than the Punjabi carer group.

The findings from this research have demonstrated support for hypotheses 2 and 3 concerning perceived stress and coping. By doing so, it has shown that the experience of caring for older people varies for different cultural groups. This research has further indicated the need for more user sensitive services for carers in general and the need for a more equitable service provision to carers who form a minority within a minority.

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## APPENDIX ONE

### NENE COLLEGE NORTHAMPTON DEPARTMENT OF PSYCHOLOGY

Post graduate research concerning the lives of Gujarati, Punjabi and white indigenous carers of older people in the County of Northamptonshire.

Case number: \_\_\_\_\_ 1

Gender of carer: 1 Male  
2 Female \_\_\_\_\_ 2

Carer address: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Telephone number: \_\_\_\_\_

District: \_\_\_\_\_ 3

Date: \_\_\_\_\_

Interviewer: \_\_\_\_\_ 4

Source of Informant: \_\_\_\_\_ 5

Pat Gibson  
Nene Centre for Research  
Nene College Northampton  
Moulton Park  
Northampton  
NN2 7AL  
Tel: 01604 735500

Thank you for agreeing to take part in this interview. The questions you will be asked concern many issues relating to your experience of caring for an older person or relative in the community.

The research being conducted will look particularly at the physical, emotional, psychological and financial aspects of looking after or helping older people, and how you, the carer, feel about this valuable role. It will also address any problems associated with access and appropriateness of information and services provided by health, social, voluntary and community agencies.

May I also take this opportunity to assure you that all information given will be treated in the strictest confidence and will only be used for analysis in relation to this study. Please feel free to ask about anything you are unsure of.

## SECTION ONE

### THE NATURE OF CARE

May I begin by asking some general questions concerning you and X  
(Use the cared-for person's name).

1. Who is it you look after or care for?

- 1 Spouse or partner
- 2 Mother
- 3 Father
- 4 Mother-in-law
- 5 Father-in-law
- 6 Other relative
- 7 Friend or neighbour
- 8 Other-please specify \_\_\_\_\_ 6

2. X's gender

- 1 Male
- 2 Female \_\_\_\_\_ 7

**\* FROM THIS POINT ON USE THE CARED-FOR OLDER PERSON'S NAME WHERE POSSIBLE (X DENOTES USE OF THE NAME)**

3. How long has X needed the care you now need to provide?

- 1 0-6 months
- 2 7-12 months
- 3 1-5 years
- 4 6-10 years
- 5 11-15 years
- 6 15+ years \_\_\_\_\_ 8

4. You have been identified as a 'carer', do you see yourself as the main carer in terms of looking after X?

- 1 Yes
- 2 No \_\_\_\_\_ 9

If not, why not?

**\* RECORD VERBATIM**

\_\_\_\_\_ 10

5. How did you first come to realise that you were a carer?

- 1 See it as a family role
- 2 Television/radio/newspapers
- 3 Professionals/Service Providers  
(e.g. Voluntary workers, Doctor, Nurse,  
Social worker etc.)
- 4 Other carers
- 5 Other-please specify \_\_\_\_\_ 11

6. How did it come about that you took on the responsibility of caring for X?

**\* RECORD VERBATIM**

Please code main reason:

- 1 Duty
- 2 Obligation
- 3 Family pressure
- 4 Cultural norms
- 5 Love
- 6 Other-please specify \_\_\_\_\_ 12

7. How did you feel about this?

**\*RECORD VERBATIM**

\_\_\_\_\_ 13

Very favourable \_\_\_\_\_ Not at all favourable

\_\_\_\_\_ 14

8. Now may I ask you about the different kinds of help you regularly provide for X.

Please code: 1 Yes  
2 No

Do you help with:

- (1) Personal care  
(e.g. dressing, bathing, washing, shaving,  
using the toilet, incontinence care) \_\_\_\_\_ 15
- (2) Physical help  
(e.g. with walking, getting up and down stairs,  
getting in and out of bed, feeding) \_\_\_\_\_ 16
- (3) Helping with paperwork or financial matters  
(e.g. writing letters, filling in forms,  
dealing with bills, banking) \_\_\_\_\_ 17
- (4) Other practical help  
(e.g. preparing meals, shopping, gardening,  
laundry, housework, taking X to hospital/doctor's) \_\_\_\_\_ 18
- (5) Keeping him/her company  
(e.g. visiting, sitting with X, reading to X,  
talking to X, playing cards or games with X) \_\_\_\_\_ 19
- (6) Taking him/her out  
(e.g. taking X for a walk or drive, taking X  
to see relatives or friends, or to church or temple) \_\_\_\_\_ 20
- (7) Giving medicines  
(e.g. making sure X takes pills/medicine, giving  
injections, changing dressings) \_\_\_\_\_ 21
- (8) Keeping an eye on X to see he/she is all right \_\_\_\_\_ 22
- (9) Other help-please specify \_\_\_\_\_ 23

**\* If informant answered yes to giving personal care and/or physical help: Go to Q.9 and Q. 10**

**If no: Go to Q.11**

9. How do you feel about providing personal care and/or physical help?

**\* RECORD VERBATIM**

\_\_\_\_\_24

Please code main feeling:

- 1 Embarrassed
- 2 Find it distasteful
- 3 Mixed feelings
- 4 Not at all bothered or worried
- 5 Other-please specify \_\_\_\_\_25

10. How does X feel about receiving such care?

Please code main feeling:

- 1 Embarrassed
- 2 Find it distasteful
- 3 Mixed feelings
- 4 Not at all bothered or worried
- 5 Other-please specify \_\_\_\_\_26

11. Is there anything about the care you provide that you find difficult to deal with?

**\* RECORD VERBATIM**

\_\_\_\_\_27

12. What preparation, training or instruction did you receive prior to, or at the time you took on the responsibility to care for X?

**\*If none, please go to Q.14**

(1) How did you receive it?

\_\_\_\_\_28

(2) When did you receive it?

\_\_\_\_\_29

(3) In what form was it?

\_\_\_\_\_30

(4) Whom did you receive it from?

\_\_\_\_\_31

(5) Who arranged it?

\_\_\_\_\_32

13. Do you consider the preparation/training  
you have had adequate for your needs?

Very adequate \_\_\_\_\_ Not at all  
adequate \_\_\_\_\_

\_\_\_\_\_33

14. Now I would like to ask you about how sufficiently prepared  
you were for the care you now provide?

Please use as prompts and code each of the following:

1 Yes  
2 No

1 Did you feel prepared for caring \_\_\_\_\_34

2 Did you understand X's condition \_\_\_\_\_35

3 Did you fully understand any information  
and/or advice given? \_\_\_\_\_36

4 Other-please specify \_\_\_\_\_37

If responding no to any of the above, can you explain what  
the problem was?

**\* RECORD VERBATIM**

\_\_\_\_\_38

## SECTION TWO

### PHYSICAL AND PSYCHOLOGICAL ASPECTS OF CARING

Now I would like to ask you some questions about your general health and your relationship with X.

15. Over the last twelve months would you say your health, on the whole, has been good, fairly good or not good?

- |   |             |         |
|---|-------------|---------|
| 1 | Good        |         |
| 2 | Fairly good |         |
| 3 | Not good    | _____39 |

16. Do you have any long-standing illness, disability or infirmity? By long-standing I mean anything that has troubled you over a period of time, or that is likely to affect you over a period of time.

To the following please code:   1   Yes  
  2   No

- |   |                      |         |
|---|----------------------|---------|
| 1 | Heart problems       | _____40 |
| 2 | Breathing problems   | _____41 |
| 3 | Circulatory problems | _____42 |
| 4 | Arthritis            | _____43 |
| 5 | Back problems        | _____44 |
| 6 | Diabetes             | _____45 |
| 7 | Other-please specify | _____46 |

17. Do you have any medical problem or disability, which might limit your activities in helping X (i.e. are there certain things you are physically unable to do)?

- |   |     |         |
|---|-----|---------|
| 1 | Yes |         |
| 2 | No  | _____47 |

If yes, can you tell me what it is you are unable to do?

**\* RECORD VERBATIM**

\_\_\_\_\_48

18. Would you say that your physical health has suffered in any way as a result of caring for X (**Prompts-** tiredness, weight loss, further deterioration of previous health problems etc.)?

- 1 Yes  
2 No \_\_\_\_\_ 49

If yes, in what way?

**\* RECORD VERBATIM**

\_\_\_\_\_ 50

19. Would you say that your emotional health has suffered in any way as a result of caring for X (**Prompts-** you feel more anxious, depressed etc.)?

- 1 Yes  
2 No \_\_\_\_\_ 51

If yes, in what way?

**\* RECORD VERBATIM**

\_\_\_\_\_ 52

20. How would you describe any feelings of stress you might experience? (**Prompts-** easily irritated and upset, tense, feel under pressure, headaches, indigestion etc.)

**\* RECORD VERBATIM**

\_\_\_\_\_ 53

21. Do you ever feel stressed in your role as a carer?

- 1 Yes  
2 No \_\_\_\_\_ 54

Not stressed \_\_\_\_\_ Very stressed

\_\_\_\_\_ 55

**\*If participant does not feel stressed go to Q.23**

22. Can you tell me why it is that you sometimes feel stressed in your role as a carer, and what in particular causes this feeling?

**\* RECORD VERBATIM**

\_\_\_\_\_56

\_\_\_\_\_57

Having asked some general questions regarding your health, I would now like to talk about the relationship between you and X.

23. Has your relationship with X changed in any way since you took on the caring role?

**\*RECORD VERBATIM**

\_\_\_\_\_58

Please code main feeling:

- 1. Has brought you and X closer
- 2. No change in the relationship
- 3. You have mixed feelings
- 4. Strain felt on either side
- 5. Other-please specify

\_\_\_\_\_59

24. Overall how would you describe your relationship with X?

Not very good \_\_\_\_\_ Very good \_\_\_\_\_60

25. What are the benefits you may experience in caring for X?

**\*RECORD VERBATIM**

Use as prompts and code main feeling:

1. You see yourself as a better person
2. You have become more understanding of older people
3. You generally become less easily upset
4. You enjoy the challenge
5. Other-please specify \_\_\_\_\_ 61

26. What, if any, are the drawbacks you may experience in caring for X?

**\*RECORD VERBATIM**

Use as prompts and code main feeling:

1. There are no real drawbacks
2. Life tends to revolve around X
3. I have less time for myself
4. My family has suffered
5. Other-please specify \_\_\_\_\_ 62



If responding no to any items in Q.28, is there anything else about the visit which is not satisfactory, such as frequency, time, convenience or quality?

**\*RECORD VERBATIM**

\_\_\_\_ 79  
 \_\_\_\_ 80  
 \_\_\_\_ 81  
 \_\_\_\_ 82

29. Have you had any problems in getting hold of any professionals or services?

1. Yes
2. No \_\_\_\_\_ 83

If yes, can you please describe this to me?

**\*RECORD VERBATIM**

\_\_\_\_ 84  
 \_\_\_\_ 85

30. Do you find the services you are offered suitable to X's needs?

1. Yes
2. No \_\_\_\_\_ 86

If the services are not suitable, can you please tell me why?

**\*RECORD VERBATIM**

\_\_\_\_ 87  
 \_\_\_\_ 88

31. Have professionals/service providers assessed your needs (e.g. care manager, district/community nurse, social worker)?

1. Yes
2. No \_\_\_\_\_ 89

32. Do you feel that your needs are equally important to professionals/service providers?

1. Yes
2. No \_\_\_\_\_ 90

Can you please give me examples?

**\*RECORD VERBATIM**

\_\_\_\_\_ 91  
\_\_\_\_\_ 92

33. How do you view your relationship with professionals and service providers? Do you:

1. See the situation as one in which you are working together to care for X?
2. Feel taken for granted?
3. See the situation as one where the responsibility to care will no longer be yours
4. Other-please specify

Please code one of the above: \_\_\_\_\_ 93

34. Can you tell me which aids and equipment have been provided to help you care?

Please code each of the following:

0. N/A
1. Yes
2. No

- |  |           |
|--|-----------|
| 1. Wheelchair                                    | _____ 94  |
| 2. Walking aids (e.g. stick, frame)              | _____ 95  |
| 3. Toileting aids (e.g. commode, bottle, bedpan) | _____ 96  |
| 4. Incontinence aids (e.g. pads)                 | _____ 97  |
| 5. Lifting aids (e.g. straps, hoist)             | _____ 98  |
| 6. Eating/drinking aids                          | _____ 99  |
| 7. Handrails                                     | _____ 100 |
| 8. Other-please specify                          | _____ 101 |

35. Do you feel you have enough aids and equipment to care?

1. Yes
2. No \_\_\_\_\_ 102

If no, can you tell me what else you need?

\_\_\_\_\_ 103

\_\_\_\_\_ 104

36. If you need to, are you able to get hold of any help from professionals/service providers/voluntary workers in an emergency?

1. Yes
2. No
3. Don't know \_\_\_\_\_ 105

If yes, can you please tell me what they are?

\_\_\_\_\_ 106

\_\_\_\_\_ 107

37. Is there any particular service you find especially helpful (health, social, voluntary and others)?

1. Yes
2. No \_\_\_\_\_ 108

If yes, can you tell me which service and why?

\_\_\_\_\_ 109

\_\_\_\_\_ 110

38. Do you find there are any language or communication difficulties with any of the professionals/service providers/voluntary agencies you deal with?

1. Yes
2. No \_\_\_\_\_ 111

**\* If no: Go to Q.41**

39. If there is a communication difficulty, can you explain what the problem is?

\_\_\_\_\_ 112

\_\_\_\_\_ 113

40. Are you offered any interpreting services either for yourself, or X, by any of the formal services (health, social, voluntary)?

0. N/A
1. Yes
2. No \_\_\_\_\_ 114

If yes, who arranges the interpreting service?

**\*RECORD VERBATIM**

\_\_\_\_\_ 115

If no, would you like to be able to use an interpreting service?

1. Yes

2. No

\_\_\_\_\_ 116

41. Do you find the health, social, voluntary and other service providers you deal with sensitive in the following areas:

Please code each of the following:

0. N/A

1. Yes

2. No

- |                          |           |
|--------------------------|-----------|
| 1. Diet                  | _____ 117 |
| 2. Religion              | _____ 118 |
| 3. Cultural norms        | _____ 119 |
| 4. Their approach to you | _____ 120 |
| 5. Other-please specify  | _____ 121 |

Can you please give me examples?

**\*RECORD VERBATIM**

\_\_\_\_\_ 122

\_\_\_\_\_ 123

42. Have you ever experienced any prejudice from any health/social/voluntary and other service providers you deal with?

1. Yes

2. No

\_\_\_\_\_ 124

If yes, can you please give me examples?

\_\_\_\_\_ 125

\_\_\_\_\_ 126

43. In general how happy are you with the services we have spoken about (health, social, voluntary and other)?

Not very happy \_\_\_\_\_ Very happy \_\_\_\_\_ 127

44. May I now ask you about what support groups or centres you know about in your area?

Please code each of the following:

1. Yes
2. No

1. Age Concern	_____	128
2. Arthritis Care	_____	129
3. Cancer Care Support Group	_____	130
4. Care at Home Team	_____	131
5. Kettering and District Carers' Centre	_____	132
6. SERVE-Voluntary Service to the Elderly	_____	133
7. Voluntary Asian Group	_____	134
8. Your local group	_____	135
9. Other-please specify	_____	136

45. Are you in regular contact with any of the above?

Please code each of the following:

0. N/A
1. Yes
2. No

1. Age Concern	_____	137
2. Arthritis Care	_____	138
3. Cancer Care Support Group	_____	139
4. Care at Home Team	_____	140
5. Kettering and District Carers' Centre	_____	141
6. SERVE-Voluntary Service to the Elderly	_____	142
7. Voluntary Asian Group	_____	143
8. Your local group	_____	144
9. Other-please specify	_____	145

46. Have you found it, or would you find it useful to be in contact with any support group or centre, if available to you?

1. Yes
2. No \_\_\_\_\_ 146

If yes, why and if not, why not?

**\*RECORD VERBATIM**

\_\_\_\_\_ 147

Now I would like to ask some questions regarding how you feel about any help and support you receive from your family, friends and neighbours.

47. How much help do you get with the following tasks?

- **If X is the spouse/partner or the participant does not have any of the following: Code 0 for N/A**

Shopping	A lot	None	
Spouse/partner	_____	_____	_____ 148
Sisters	_____	_____	_____ 149
Brothers	_____	_____	_____ 150
Children	_____	_____	_____ 151
Other family	_____	_____	_____ 152
Friends	_____	_____	_____ 153
Neighbours	_____	_____	_____ 154

Housework	A lot	None	
Spouse/partner	_____	_____	_____ 155
Sisters	_____	_____	_____ 156
Brothers	_____	_____	_____ 157
Children	_____	_____	_____ 158
Other family	_____	_____	_____ 159
Friends	_____	_____	_____ 160
Neighbours	_____	_____	_____ 161

Childcare (if applicable)	A lot	None	
Spouse/partner	_____	_____	_____ 162
Sisters	_____	_____	_____ 163
Brothers	_____	_____	_____ 164
Children	_____	_____	_____ 165
Other family	_____	_____	_____ 166
Friends	_____	_____	_____ 167
Neighbours	_____	_____	_____ 168

Help with physical care for X	A lot	None	
Spouse/partner	_____	_____	_____ 169
Sisters	_____	_____	_____ 170
Brothers	_____	_____	_____ 171
Children	_____	_____	_____ 172
Other family	_____	_____	_____ 173
Friends	_____	_____	_____ 174
Neighbours	_____	_____	_____ 175

Help with personal care for X

	A lot	None	
Spouse/partner	_____	_____	_____ 176
Sisters	_____	_____	_____ 177
Brothers	_____	_____	_____ 178
Children	_____	_____	_____ 179
Other family	_____	_____	_____ 180
Friends	_____	_____	_____ 181
Neighbours	_____	_____	_____ 182

Other help-please specify

	A lot	None	
Spouse/partner	_____	_____	_____ 183
Sisters	_____	_____	_____ 184
Brothers	_____	_____	_____ 185
Children	_____	_____	_____ 186
Other family	_____	_____	_____ 187
Friends	_____	_____	_____ 188
Neighbours	_____	_____	_____ 189

48. Can you tell me how any help you receive is forthcoming  
i.e., do you have to ask or is it freely offered?

**\*RECORD VERBATIM**

\_\_\_\_\_ 190  
\_\_\_\_\_ 191

49. Has any help you might receive from your family, friends  
and neighbours lessened in any way as time passes?

1. Yes
2. No

\_\_\_\_\_ 192

50. How do you feel about any help and support you might receive  
from other family members?

Use as prompts and code one of the following:

1. Guilt for needing help
2. You welcome the help
3. Think they should be willing to help
4. Help is given automatically
5. Other-please specify

\_\_\_\_\_ 193

51. Is there a difference in the type of help you receive from your family, friends and neighbours?

**\*RECORD VERBATIM**

\_\_\_\_\_ 194  
 \_\_\_\_\_ 195  
 \_\_\_\_\_ 196

52. How happy are you with the quality i.e., type and quantity of help from your family?

**\*If not applicable: Code 0 for N/A**

Very happy \_\_\_\_\_ Not very happy \_\_\_\_\_ 197

53. How happy are you with the quality i.e., type and quantity of help from your friends?

**\*If not applicable: Code 0 for N/A**

Very happy \_\_\_\_\_ Not very happy \_\_\_\_\_ 198

54. How happy are you with the quality i.e., type and quantity of help from your neighbours?

**\*If not applicable: Code 0 for N/A**

Very happy \_\_\_\_\_ Not very happy \_\_\_\_\_ 199

55. Is there any one you can confide in when you feel the need to talk to someone?

Please code each of the following:

1. Yes
2. No

- |   |           |
|---|-----------|
| 1. Family member                          | _____ 200 |
| 2. Friend                                 | _____ 201 |
| 3. Religious leader                       | _____ 202 |
| 4. Professional e.g., GP, Counsellor etc. | _____ 203 |
| 5. Other-please specify                   | _____ 204 |

56. Do you feel that some religious/spiritual practice is helpful?

1. Yes
  2. No
- \_\_\_\_\_205

If yes, can you please give me examples?

\_\_\_\_\_206  
\_\_\_\_\_207

57. On the whole would you say you feel appreciated by others in caring for X?

1. Yes
  2. No
- \_\_\_\_\_208

If yes, by whom is this shown?

\_\_\_\_\_209  
\_\_\_\_\_210

58. Do you have people from your own ethnic background around you, i.e., living near you?

1. Yes
  2. No
- \_\_\_\_\_211

59. Do you sometimes feel very alone and responsible for the care you provide?

1. Yes
  2. No
- \_\_\_\_\_212

If yes, can you tell me how this makes you feel?

**\*RECORD VERBATIM**

\_\_\_\_\_213

60. Which particular service/services from health, social, voluntary and other providers do you see as being important to you in caring for X in the future?

Please code each of the following:

1. Yes
2. No

1. Luncheon/ community clubs	_____	214
2. Day centres	_____	215
3. Respite care	_____	216
4. Sitting services (day and/or night)	_____	217
5. Community nurses/social worker	_____	218
6. Carers' centre	_____	219
7. Home-help	_____	220
8. Meals-on wheels	_____	221
9. Other-please specify	_____	222

What else do you feel you would like to add regarding any services offered by health, social, voluntary and other service providers and any help and support offered by family, friends and neighbours?

## SECTION FOUR

### COPING WITH CARING

Many people see their caring role as a normal part of being in a family or a community, however the questions in this section on coping with caring still relate to you in your everyday life as a carer for X.

61. Do you have the time to do the things you normally like to do whilst caring for X?

- |        |           |
|--------|-----------|
| 1. Yes |           |
| 2. No  | _____ 223 |

62. Do you have to make specific arrangements for X in order to enjoy the things you normally like to do?

- |        |           |
|--------|-----------|
| 1. Yes |           |
| 2. No  | _____ 224 |

If yes, how do you go about this?

\_\_\_\_\_ 225

63. Do you regularly get some kind of break from your caring activities (e.g. X attending a day centre, respite care, help with sitting, a holiday etc.)

- |        |           |
|--------|-----------|
| 1. Yes |           |
| 2. No  | _____ 226 |

If yes, can you tell me what kind of break you get?

**\*RECORD VERBATIM**

\_\_\_\_\_ 227

64. Which activities do you find most helpful to your wellbeing or that makes you happy?

Please code up to 4 of the following main activities: 1. Yes

- |                             |           |
|-----------------------------|-----------|
| 1. Sport/Leisure activities | _____ 228 |
| 2. Reading                  | _____ 229 |
| 3. Television/radio         | _____ 230 |
| 4. Socialising              | _____ 231 |
| 5. Keeping busy             | _____ 232 |
| 7. Religious activities     | _____ 233 |
| 8. Relaxation               | _____ 234 |
| 9. Other-please specify     | _____ 235 |

65. How do you/would you feel about leaving X in the care of someone else (either professional, voluntary and/or family, friends etc.)?

**\*RECORD VERBATIM**

Very happy \_\_\_\_\_ Not very happy \_\_\_\_\_ 236

66. Are you able to attend social events etc. without worrying about X?

1. Yes
2. No \_\_\_\_\_ 237

If yes, can you tell me who takes care of X?

\_\_\_\_\_ 238

67. Do you yourself regularly receive social visits from family, friends etc.?

1. Yes
2. No \_\_\_\_\_ 239

68. Do you set any limits with the care you provide?

Please code each of the following:

1. Yes
  2. No
- 
1. Not carry out certain activities \_\_\_\_\_ 240
  2. Keep a physical space for yourself and/or the rest of the family e.g. a separate room \_\_\_\_\_ 241
  3. Accept there are things you cannot change and therefore don't worry too much \_\_\_\_\_ 242
  4. Compromise with what you are prepared to do \_\_\_\_\_ 243
  5. Other-please specify \_\_\_\_\_ 244

69. How do you deal with a stressful or difficult situation in your caring role?

Code each of the following:

1. Yes
2. No

- |   |           |
|---|-----------|
| 1. Do you think about ways of overcoming problems     | _____ 245 |
| 2. Do you avoid problems by ignoring them             | _____ 246 |
| 3. Do you avoid problems by keeping busy              | _____ 247 |
| 4. Do you try not to worry                            | _____ 248 |
| 5. Do you tend to eat/drink/smoke/take pills more     | _____ 249 |
| 6. Do you try to see the positive side of a situation | _____ 250 |
| 7. Do you let your feelings out somehow               | _____ 251 |
| 8. Do you sleep more                                  | _____ 252 |
| 9. Do you avoid people                                | _____ 253 |
| 10. Do you make a plan of action to follow            | _____ 254 |
| 11. Other-please specify                              | _____ 255 |

**\*RECORD VERBATIM**

70. Is there any other specific action you use to cope with or certain situations in your caring role (**Prompts-** seek information, go for a walk, keep to a routine, be assertive, leisure activities etc.)

1. Yes
2. No \_\_\_\_\_ 256

If yes, can you tell me exactly what you do?

**\*RECORD VERBATIM**

\_\_\_\_\_ 257  
\_\_\_\_\_ 258

71. Problems vary, but in a difficult situation what would you say works best for you?

**\*RECORD VERBATIM**

\_\_\_\_\_ 259  
\_\_\_\_\_ 260

72. Do you think you are able to balance the needs of both yourself and X in a satisfactory way?

1. Yes
2. No

\_\_\_\_\_261

Can you please give me examples?

**\*RECORD VERBATIM**

\_\_\_\_\_262

\_\_\_\_\_263

73. Your caring role may change as time goes by, how do you see yourself dealing with the situation in the future?

**\*RECORD VERBATIM**

\_\_\_\_\_264

74. Overall, how do you feel you generally cope with your caring role and everyday life?

**\*RECORD VERBATIM**

Not very well \_\_\_\_\_ Very well \_\_\_\_\_265

What else would you like to say on coping in your role as a carer?

## SECTION FIVE

### EMPLOYMENT AND INCOME

In this section I would just like to ask a few questions regarding any paid work, voluntary work, household income and costs incurred through caring for X.

**\*IF INFORMANT IS RETIRED: GO TO Q.82**

75. Are you in paid work at the moment?

1. Yes
2. No \_\_\_\_\_266

**If no: Go to Q.80**

If yes, is this:

1. Full time
2. Part time \_\_\_\_\_267

76. What do you do in your paid work i.e., your position or job?

**\*RECORD VERBATIM**

\_\_\_\_\_268

77. Has your caring role affected the hours of paid work you are able to do?

1. Yes
2. No \_\_\_\_\_269

If yes, can you tell me how?

**\*RECORD VERBATIM**

\_\_\_\_\_270

78. Does your caring role affect your paid work in any of these ways?

Code each of the following:

1. Yes
2. No

1. Type of work you are able to do \_\_\_\_\_271
2. Number of hours \_\_\_\_\_272
3. Promotion prospects \_\_\_\_\_273

- |                         |          |
|-------------------------|----------|
| 4. Course attendances   | _____274 |
| 5. Holiday entitlements | _____275 |
| 6. Other-please specify | _____276 |

79. Can you take time off work to take X to the doctor's etc.?

- |        |          |
|--------|----------|
| 1. Yes |          |
| 2. No  | _____277 |

If yes, do you have to make the time up?

- |        |          |
|--------|----------|
| 1. Yes |          |
| 2. No  | _____278 |

80. If you are not currently in paid work, are you seeking any?

- |        |          |
|--------|----------|
| 1. Yes |          |
| 2. No  | _____279 |

81. Did you have to give up work in order to care for X?

- |        |          |
|--------|----------|
| 1. Yes |          |
| 2. No  | _____280 |

If yes, what did you do in your paid work and when did you give it up?

**\*RECORD VERBATIM**

_____281
_____282

82. Do you do any voluntary work i.e., unpaid work outside the home?

- |        |          |
|--------|----------|
| 1. Yes |          |
| 2. No  | _____283 |

If yes, can you tell me about this?

_____284
----------

83. Do you receive any state benefits as a result of caring for X?

Code each of the following:

- |        |           |
|--------|-----------|
| 1. Yes |           |
| 2. No  | _____ 285 |

- |                           |           |
|---------------------------|-----------|
| 1. Income support         | _____ 286 |
| 2. Housing benefit        | _____ 287 |
| 3. Invalid care allowance | _____ 288 |
| 4. Family credit          | _____ 289 |
| 5. Other-please specify   | _____ 290 |

84. Does X receive any of the following benefits?

Code each of the following:

- |        |  |
|--------|--|
| 1. Yes |  |
| 2. No  |  |

- |                                    |           |
|------------------------------------|-----------|
| 1. State retirement pension        | _____ 291 |
| 2. Private pension                 | _____ 292 |
| 3. Occupational pension            | _____ 293 |
| 4. Disability pension              | _____ 294 |
| 5. Income support                  | _____ 295 |
| 6. Disability living allowance:    |           |
| a) an attendance or care allowance | _____ 296 |
| b) a mobility allowance            | _____ 297 |
| 7. Housing benefit                 | _____ 298 |
| 8. Other-please specify            | _____ 299 |

85. Did you or X have any difficulty obtaining any of the benefits?

- |        |           |
|--------|-----------|
| 1. Yes |           |
| 2. No  | _____ 300 |

If yes, can you tell me which particular benefit (s) you and/or X had any difficulty obtaining and why?

**\*RECORD VERBATIM**

_____ 301
_____ 302

86. Do you, on behalf of X, have to pay for any of the following services?

Code each of the following:

1. Yes
2. No

- |  |           |
|--|-----------|
| 1. Transport services (not public transport) | _____ 303 |
| 2. Day care                                  | _____ 304 |
| 3. Luncheon clubs                            | _____ 305 |
| 4. Home-help                                 | _____ 306 |
| 5. Meals-on-wheels                           | _____ 307 |
| 6. Sitting services                          | _____ 308 |
| 7. Other-please specify                      | _____ 309 |

87. Does payment for any of the above, or any other services you receive, cause you or X financial problems?

1. Yes
2. No \_\_\_\_\_ 310

If yes, can you tell me what they are?

\_\_\_\_\_ 311  
\_\_\_\_\_ 312

88. Are there any other ways in which you have suffered financially since taking on the caring role (**Prompts**-extra costs, laundry, telephone calls, petrol, heating, special foods etc.)

1. Yes
2. No \_\_\_\_\_ 313

If yes, can you please give me examples?

\_\_\_\_\_ 314  
\_\_\_\_\_ 315

89. Do you feel you have enough income to care satisfactorily?

1. Yes
2. No \_\_\_\_\_ 316

If no, can you tell me, which benefit or other income you need?

\_\_\_\_\_ 317

## SECTION SIX

### SOCIAL AND DEMOGRAPHIC INFORMATION

In this penultimate section I would just like to ask a few general questions to summarise what we have already talked about.

90. May I ask why X needs support or care?

Please code each of the following:

1. Yes
2. No

- |   |           |
|---|-----------|
| 1. Physical disability/limitation                   | _____ 318 |
| 2. Sensory impairment (e.g., blindness or deafness) | _____ 319 |
| 3. Mental health problems                           | _____ 320 |
| 4. Learning disabilities                            | _____ 321 |
| 5. Supervision                                      | _____ 322 |
| 6. Other-please specify                             | _____ 323 |

91. If X does not live with you, how far away does he/she live?

If X lives with informant; Code 0 for N/A

- |                     |           |
|---------------------|-----------|
| 1. Less than 1 mile |           |
| 2. 1-4 miles        |           |
| 3. 5-10 miles       |           |
| 4. 11+ miles        | _____ 324 |

92. Age range of X?

- |                |           |
|----------------|-----------|
| 1. 55-75 years |           |
| 2. 76-90 years |           |
| 3. 90+ years   | _____ 325 |

93. Your age group?

- |                |           |
|----------------|-----------|
| 1. 18-25 years |           |
| 2. 26-40years  |           |
| 3. 41-55 years |           |
| 4. 56-70 years |           |
| 5. 71+ years   | _____ 326 |

94. How many children (under the age of 16) are you responsible for?

\_\_\_\_\_ 327

95. How do you define your ethnicity?

1. Indian Gujarati
2. Indian Punjabi
3. White European
4. White-other
5. Other-please specify \_\_\_\_\_ 328

96. What is the ethnicity of X?

1. Indian Gujarati
2. Indian Punjabi
3. White European
4. White-other
5. Other-please specify \_\_\_\_\_ 329

97. What is your religion?

1. Baptist
2. Buddhist
3. Catholic
4. Church of England
5. Evangelist
6. Hindu
7. Methodist
8. Muslim
9. Sikh
10. Other-please specify \_\_\_\_\_ 330

98. What language/languages do you speak?

Please specify:

First language \_\_\_\_\_ 331  
 Second language \_\_\_\_\_ 332

99. How long have you lived in Britain?

1. Less than 1 year
2. 1-5 years
3. 6-15 years
4. 16-25 years
5. 26+ years
6. All your life \_\_\_\_\_ 333

• **IF X DOES NOT LIVE WITH INFORMANT:  
GO TO Q. 101**

100. Is your home?

1. Detached house
2. Semi-detached house
3. Terraced house
4. Council house/flat
5. Privately owned apartment
6. Warden controlled accommodation
7. Other-please specify \_\_\_\_\_ 334

101. On average how many hours per day do you spend caring for X  
(including time you just need to be there and including travelling  
to and from his/her home)?

1. 1-2 hours
2. 3-5 hours
3. 6-9 hours
4. 10-12 hours
5. 13+ hours \_\_\_\_\_ 335

102. Thinking about the total time you spend caring for X, about  
how long altogether on average do you spend each week looking  
after or helping him/her?

1. 0-4 hours per week
2. 5-9 hours per week
3. 10-19 hours per week
4. 20-34 hours per week
5. 35-49 hours per week
6. 50-99 hours per week
7. 100 or more hours per week
8. Other-please specify \_\_\_\_\_ 336

103. Could you please tell me which group represents you and your  
husband/partner's average net monthly income?

By net income I mean income after deductions for income tax, National  
Insurance etc.

**DO NOT PROBE IF INFORMANT APPEARS HESITANT ON THIS  
QUESTION**

**IF INFORMANT IS HAPPY TO DISCLOSE NET MONTHLY INCOME: SHOW CARD C1 AND CODE ACCORDINGLY**

\_\_\_\_337

What else would you like to add to this whole interview, which you feel is important and, which concerns your role as a carer?

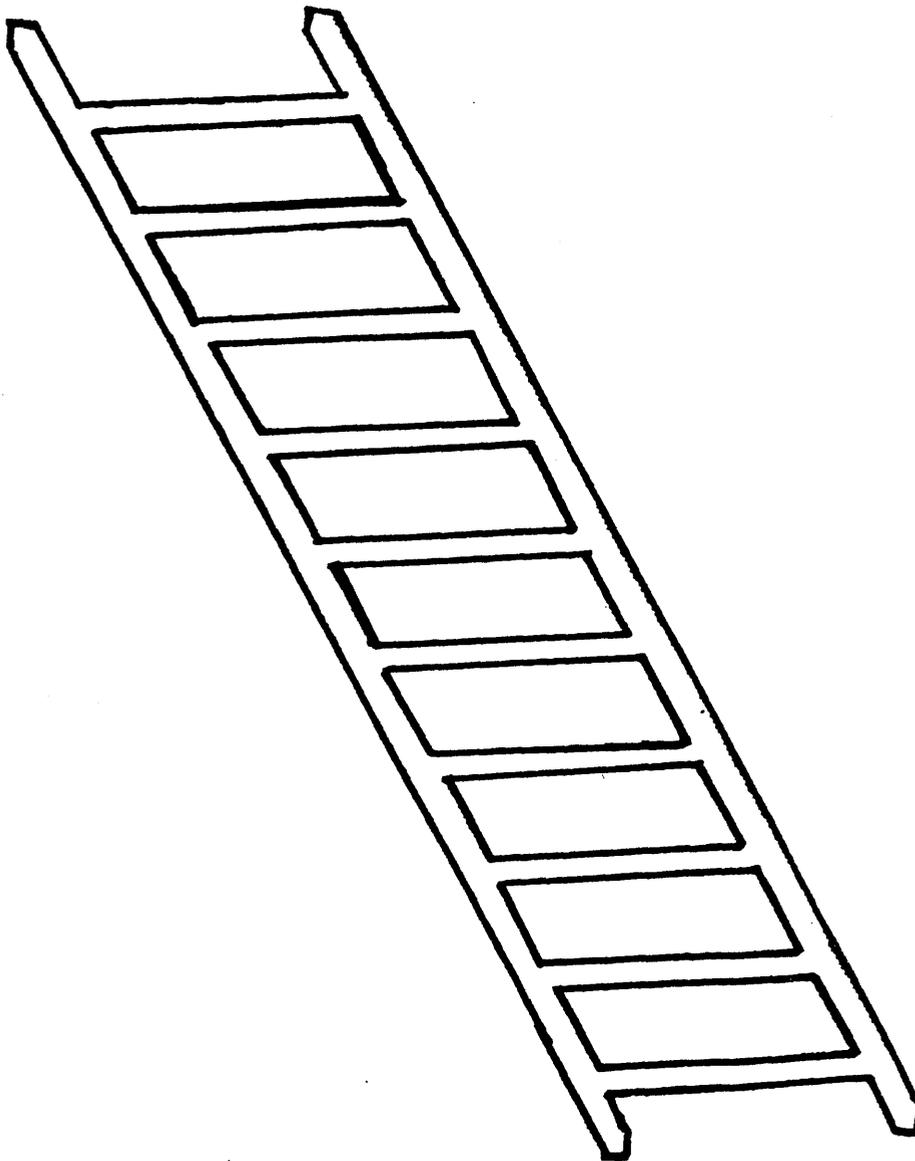
Again, thank you for all your help and time in allowing this interview. It is very much appreciated.

**All information given remains totally confidential and will only be used for research purposes.**

**SECTION SEVEN****CANTRIL'S LADDER**

Finally, I would just like to ask you to fill in these two quick and easy measures.

This is a picture of a ladder. If the top of the ladder represents the best possible life for you and the bottom represents the worst possible life for you, where would you place yourself on the ladder?



**SECTION EIGHT****HEALTH QUESTIONNAIRE**

Please code each of the following:

1. Yes
2. No

Do you often have backache?	_____ 339
Do you feel tired most of the time?	_____ 340
Do you often feel miserable or depressed?	_____ 341
Do you often have bad headaches?	_____ 342
Do you often get worried about things?	_____ 343
Do you usually have great difficulty in falling asleep or staying asleep?	_____ 344
Do you wake unnecessarily early in the morning?	_____ 345
Do you wear yourself out worrying about your health?	_____ 346
Do you often get into a violent rage?	_____ 347
Do people often annoy and irritate you?	_____ 348
Have you at times had a twitching of the face, head or shoulders?	_____ 349
Do you often suddenly become scared for no good reason?	_____ 350
Are you scared to be alone when there are no friends near you?	_____ 351
Are you easily upset or irritated?	_____ 352
Are you frightened of going out alone or of meeting people?	_____ 353
Are you constantly keyed up and jittery?	_____ 354
Do you suffer from indigestion?	_____ 355
Do you often suffer from a stomach upset?	_____ 356

Is your appetite poor?	_____357
Does every little thing get on your nerves and Wear you out?	_____358
Does your heart often race like mad?	_____359
Do you often have bad pain in your eyes?	_____360
Are you troubled with rheumatism or fibrositis?	_____361
Have you ever had a nervous breakdown?	_____362
<b>TOTAL</b>	_____363

**C1**

- 1    Less than £200
- 2    £201-£250
- 3    £251-£350
- 4    £351-£450
- 5    £451-£600
- 6    £601-£800
- 7    £801-£1000
- 8    £1001-£1300
- 9    £1301-£1700
- 10   £1700+
- 11   Unable to answer

## APPENDIX 2

### A BASIC OUTLINE OF THE RESEARCH

#### **Introduction**

My interest in the present research initially arose out of the fact that, over the past twenty years, I have worked with older people as a formal carer. I can go home at the end of a shift, but I often wondered how patients and their families coped when they were discharged back into the community. Therefore, when I was required to carry out a small study for my degree, I decided to look into the lives of informal carers of older people. The experience of seeing the loyalty, love and unflinching support given to older people both heartened and humbled me. Many of these carers were looking after a heavily dependent person with little or no help from other family and friends or health and social services. A few were of a similar age to the person they were caring for, and were not in good health themselves. I have to admit that my eyes were completely opened by what I found. However, when researching the literature about informal caring, I found there was very little on these carers from minority ethnic groups. Hence, when the opportunity arose for me to carry out further research, I was pleased to be able to explore whether any similarities or differences existed in the situations and experiences of informal carers in different cultural groups. I very much hope that this research will be able to advance our knowledge about, and understanding of, carers of older people in a multi-ethnic society.

#### **General Background to the Research**

One of the most important social policy issues of today is to provide care in the community to people who because of frailty, illness or disability are unable to care for themselves. This policy is based on the view that it is in the best interests of those requiring care, and it is a view generally shared by the dependants themselves and their family, relatives and friends. The implementation of this major policy objective has resulted in the NHS and Community Care Act, 1990.

Aspirations to improve care in the community were first articulated in relation to people with mental health problems who were gradually being deinstitutionalised. The political and social concerns have since focused on older people who have been identified as a priority group for community care initiatives. The main reason for this is the expected increase in the numbers of older people compared to the rest of the population (OPCS, 1983). Although many older people

are in good health and are able to look after themselves in their own homes, the incidence and severity of disability increase with age. The number of people likely to require care is therefore expected to increase. However, at the same time, changes in family size, decreasing numbers of women (the traditional carers), patterns of increasing divorce and remarriage (making responsibilities for parental care less clear), and women's participation in the labour market have raised concerns about the capacity of 'the community' to care for this increased number of people (Parker, G., 1990). Fundamental to this provision of care are the **informal carers** i.e., family, relatives, friends and neighbours of older people.

Until recently the role of informal carers had been ignored by government and society at large, however the premise included in the White Paper (1989) 'Caring for People' specifically spells out support for carers. A key objective is to ensure that practical support for carers is a high priority in the planning, development and delivery of care services. Changes heralded in the NHS and Community Care Act (1990) enable local social and health authorities to jointly share responsibilities in the provisions of social and health care and that private and voluntary agencies and informal carers together provide a 'network' of care. Key workers from local authority social services will manage and co-ordinate individual 'packages of care' for each client and their carer. Support for older people by the community is therefore currently considered a cost-efficient solution to aged care. However the implications of this government policy for carers needs to be thoroughly addressed if this approach is to be considered effective and fair for all members of our multi-ethnic and multi-cultural society.

### **Typology of carers**

Until the mid 80s any estimate of the numbers of people caring for older people or other dependants was, on the whole, a matter of informed guesswork. At the request of the Department of Health and Social Services, the 1985 General Household Survey (GHS), for the first time, included questions on carers, which clearly indicated the numbers and characteristics of carers nationally. Informal carers were defined as people who were looking after, or providing some regular service for, a sick, handicapped or elderly person living in their own or in another household.

The 1990 GHS survey (a monitor updating the main findings of the 1985 GHS) indicated that more than **6.8 million** carers, i.e., 1:7 adults in Britain are carers. Carers are ordinary people of every age, ethnicity, class and religion. Information from the GHS has shown that 23% of carers were spending more than 20 hours a week caring, and that 11% were spending more than

50 hours a week. For many, caring is a 24 hours a day, 7 days a week job. The 1990 GHS also revealed that the proportion of those requiring care aged 85 or over had increased by 5% from 1985 to 20% in 1990, and more than half of carers were supporting older people aged 75 or over. These numbers strongly support the expected major increase of older people in our community who will require care.

### **Difficulties faced by carers**

People often do not realise they are carers and do not make the connection between what they do in a family relationship and the informal caring role. Caring usually occurs gradually, and for many, their role is envisaged as a short-term one, but then they find themselves in a long-term situation, because of increasing frailty in the older cared for person. Caring takes place in a relationship, and it is the nature and history of that relationship, which gives rise to caring for someone. Many carers see their role as one of duty and obligation i.e. an involuntary role. By its very nature, caring might impose a burden, and once the role is taken on, it is very difficult to shed. Although caring also has its benefits, it may involve considerable costs, not only in monetary terms, but also in social and psychological terms. Many carers find that their health suffers and deteriorates as a result of exhaustion and stress (Watkins et al., 1991). Many, especially older spouse carers, also become lonely and isolated, particularly carers who are not indigenous to this country. Hence, this research is especially interested in the psychosocial aspects of caring (stress, coping and social support).

### **Minority Ethnic Issues**

Research so far has shown that minority groups have not received appropriate, accessible and adequate services to meet their needs (Norman, 1985; Fenton, 1987; McCalman, 1990, Bowling, 1990, 1991; Walker and Ahmad, 1994). It is argued, however, that although race aspects of the NHS and Community Care Act, 1990 have not been specifically highlighted, the new legislation does offer Local Authorities, for the first time, the opportunity to change this 'colour-blind' situation and positively incorporate race equality principles and practice into their community care implementation. In Paragraph 2.9 of "Caring for People", it was stated:

*'The Government recognises that people from different cultural backgrounds may have particular care needs and problems. Minority communities may have different concepts of community care and it is important that service providers are sensitive to these variations. Good community care will take account of the*

*circumstances of minority communities and will be planned in consultation with them'.*

(Cmnd. 849, 1989: 10-11)

Such a statement then emphasises user views and it is in this context that the needs of black and minority ethnic older people and their carers can actively be incorporated into service provision. Previously the ageing of Britain's black and minority ethnic older people and their carers had not really been considered by policy makers in the health and social services probably because of the belief that black minority ethnic communities, and specifically Asian families, are assumed to take full responsibility for older relatives. In addition, it has been argued that health, social and community service provision that is available is ethnocentric and based on racist assumptions (Cheetham, 1982; Patel, 1990; Williams, 1990; Dominelli, 1991; Bowes and Domokos, 1993; Twigg and Atkin, 1994). Given these factors, there is therefore little information available on the experience of black and minority ethnic carers. This study therefore aims to address some of these shortcomings by exploring some of the main issues regarding the position, circumstance and experience of carers of older people from different cultural groups.

I thank you in advance for your interest and co-operation, and I sincerely hope that you will enjoy the interviewing. I very much appreciate the contribution you are making towards this research. Please feel free to contact me anytime.

## APPENDIX 3

### INTERVIEW GUIDELINES

Before we look at some basic guidelines for interviewing, there are just a few points that need to be brought to your attention.

- Your name will have been given to the informant prior to the interview, however please take with you your letter of introduction.
- Make arrangements for the interview for a mutually convenient time. Also, please ensure that it will take place in privacy, in order that the informant's responses will not be inhibited. For example, ask when the supported person attends a day centre or takes a nap etc.
- Before the interview commences, please assure the informant that all information given remains totally confidential and that their anonymity is guaranteed. Also, please explain that the basic aims of the interview are to look at carers' experiences, how they feel about their role, what support they receive and generally, how they cope with caring and their everyday life.
- **Your safety is of the utmost importance**  
Whenever possible, inform someone of your whereabouts before the interview. If at anytime during the interview you feel uncomfortable or threatened, please make a logical excuse to leave immediately.

#### The Interview Schedule

- The interview schedule contains both closed and open questions.
- Please translate or read questions as worded where possible, otherwise responses become invalid, as different questions are being asked.
- Please ask the questions in the correct order.
- Please ask every question which applies.
- Please follow the routing instructions e.g., if yes: Go to Q.
- Once the interview has been completed, please debrief the informant for example, by ensuring they are happy with the information they have given you. Offer any of the information leaflets you have been provided with and/or any other relevant contact names and telephone numbers.
- Before leaving, please thank the informant for their help and **always** ask for names of other carers known to them. Should the informant appear hesitant about providing the names of other carers, suggest he/she contact them first to gain permission for the interview.

### **Interviewing Techniques**

Interviewing techniques should ideally meet 2 requirements:

1. It must not bias the responses;
2. It must ensure a socially effective discourse that helps and motivates the informant to respond adequately.

To maximise informants responses:

- Express sympathetic understanding and show interest in the informant's circumstance.
- Pay attention throughout the interview.
- Use a gentle tone of voice.
- Use a steady speed when asking the questions with correct intonation and emphasis.
- Ensure that you have understood the responses and that the answers given are adequate.
- Never show bias to responses, such as approval or disapproval, as this may make the informant believe certain answers are more acceptable.
- Repeat the answers e.g., yes or no to ensure that the informant knows you have understood his/her reply and clarify answers as necessary.
- Where necessary repeat the question.
- Probe only non-directively to avoid suggestion for example, by using which, what, why, how, can you explain etc.

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Post graduate research concerning the lives of Gujarati, Punjabi and white indigenous carers of older people in the county of Northamptonshire.

This is to verify that  
working on behalf of the researcher for the above project.

is an interviewer

If you wish to confirm the identity of the interviewer, please telephone either Pat Gibson or Dr Ruchira Leisten on (01604) 735500 and ask for extension 2510.

Thank you for agreeing to this interview and for giving up your valuable time. Any information given will be treated in the strictest confidence.

Pat Gibson