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the University of Leicester.

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DECLARATION

This thesis constitutes original work by the named author. It has not been submitted for any other qualification, or to any other institution.

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WORD COUNT

	Excluding References	Including References
Abstract	286	286
Literature Review	6,170	7,160
Research Report	11,958	13,380
Critical Appraisal	4,964	5,238
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Addendum:	111,699	

The literature review (Section A), research report (Section B) and Critical Appraisal (Section C) follow the general style of the British Journal of Clinical Psychology (Appendix A). Referencing therefore follows American Psychological Association guidelines.

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ABSTRACT

AN EXPLORATION OF RELIGIOUS COPING IN CARERS OF PEOPLE WITH PSYCHOSIS.

Thesis submitted for the degree of Doctorate in Clinical Psychology by Sarah Longbotham

This thesis comprises of three sections:

Section A: Literature Review
Title: Is there a relationship between prayer-related expectations and physical health outcome in randomised controlled trials examining distant intercessory prayer?

This review evaluated the overall effectiveness of distant intercessory prayer and considered how expectations of distant intercessory prayer might impact on its effectiveness as an adjunct to standard medical interventions. Electronic databases (Psych Info, ISI Web of Science, Psych Articles, Embase and Medline) were searched. Results suggest low levels of reliability and validity across studies, with conclusions being restricted by inadequate trial procedures.

SECTION B: Research Report
Title: An Exploration of Religious Coping in Carers of People with Psychosis.
Aims.
This study aimed to explore how carers of people with psychosis used religion in coping with their caring role.
Method.
Ten carers of people with psychosis were interviewed using semi-structured interviews. Research was conducted and analysed using Grounded Theory.
Results.
The core category of "using religion as a balancing act" emerged from the analysis. Five main categories were also identified. These categories were inter-related and comprised a process model, illustrating how the participants used religion in coping with their roles as carers.
Conclusions.
Results suggested that participants' religious beliefs contributed to flexible coping. It is suggested that coping related to a responsibility continuum. At one end of the continuum there was individual responsibility to change challenging situations, and at the other responsibility was attributed to God. How participants were placed on this continuum was influenced by several factors, including relationships with mental health services. The clinical implications of these processes are discussed.

SECTION C: Critical Appraisal
The researcher draws on information from her reflexive journal and research memos in highlighting how the author negotiated choices and dilemmas encountered in the research process.

SECTION A: Literature Review

Is there a relationship between prayer-related expectations and physical health outcome in randomised controlled trials examining distant intercessory prayer?

1. Abstract

Objectives. This review aimed to evaluate the overall effectiveness of distant intercessory prayer and consider how expectations of distant intercessory prayer might impact on its effectiveness as an adjunct to standard medical interventions.

Methods. Electronic databases (Psych Info, ISI Web of Science, Psych Articles, Embase and Medline) were searched. Articles that specified the use of "distant intercessory prayer" in physical health or mental health settings between 1887 and September 2007 were included within the review. Nine studies were found to meet inclusion criteria and consequently these studies comprised relevant data.

Results. The research examined stemmed from the clinical specialities of renal care, cardiac care, child psychiatry, rheumatoid arthritis, bloodstream infection and in vitro fertilisation. The majority of papers reviewed suggested positive health benefits to be accrued from distant intercessory prayer. Results also suggest that prayer-related expectations might have been relevant for all studies reviewed. Limitations stemming from research in this area include lack of validated outcome measures and longitudinal design, small sample sizes and severe restrictions in managing treatment group specificity.

Conclusions. Results suggest low levels of reliability and validity across studies, with conclusions being restricted by inadequate trial procedures. Recommendations are made for studies to take baseline and follow-up measures of prayer expectation and to account for this when analysing results. Due to the lack of rigour within studies and confusion regarding the underlying theoretical underpinnings of the research, recommendations regarding the use of intercessory prayer in physical health care settings cannot be made.

2. The Relationship Between Religious Activity and Health

Religious coping, for example prayer and religious social support has high prevalence rates within specific populations (Koenig & Larson, 2001). For example, in a sample of hospitalised, medically unwell older adults, 85% held religious beliefs and 40% reported that their religious faith was the most important coping factor (Koenig, 1998). High prevalence rates of religious coping have prompted research investigating whether there might be associated health benefits. Several studies have suggested positive implications for religious coping in different client populations: these include the elderly (Ellison & Levin, 1998), those coping with drug and alcohol issues (Gorsuch, 1995), coping with trauma (King & Crowther, 2004) and people living with HIV (Tuck, McCain & Elswick, 2001).

In comparison with studies investigating direct religious health benefits there has been relatively less research examining the effects that religious practice might have for recipients of religious activity, for example health benefits for people who are prayed for. Intercessory prayer is commonly used by multiple faith groups who believe that prayer is a personal communication between an intercessor, (or group of intercessors) and God, on behalf of another person who is in need (Roberts, Ahmed & Hall, 2007). Galton (1872, cited in Sloan & Ramakrishnan, 2006) suggested that it was extremely unlikely that there were any health benefits from distant intercessory prayer. He observed that state sovereigns who were the regular recipients of public prayer requesting increased health and longevity were relatively short lived. However because these findings were observational and there are now methodologically much more rigorous and stringent approaches, attempts have been made to expose intercessory prayer to experimental investigations within randomised controlled trials.

More recently, there has been an increased interest in intercessory prayer and its potential to alleviate physical and mental health problems. Two types of intercessory prayer have been studied. Firstly direct contact prayer, in which the intercessor lays hands on the person being prayed for. Secondly distant intercessory prayer in which there is no necessary contact between those who are offering the prayer and those receiving it. Most research has concentrated on distant intercessory prayer, however Beutler, Attevelt and Schouten (1988) evaluated the effects of both direct and indirect prayer on people with hypertension and found that whilst there was no difference between the groups in blood pressure control, direct laying on of hands was associated with enhanced psychological "well-being". Thus within studies evaluating the effectiveness of prayer there are often measures assessing psychological well-being, as well as those which focus primarily on physical health changes, and these can differ depending on the type of prayer that is being examined.

Despite the increase in research evaluating the efficacy of intercessory prayer, there has been little attention given to examining the effect that participant expectation of prayer might have on physical health outcome. Green (1993) suggested that it was the expectation of the utility of prayer that reduced anxiety levels in participants rather than the intercessory prayer per se. In addition Matthews, Conti and Sireci (2001) suggested that the effects of intercessory prayer were indistinguishable from expectancy. These findings suggest that reports of health improvements within intercessory prayer studies may stem from the prayer recipient's beliefs about the benefits of prayer. Empirical studies have indicated that motivation can be strongly linked with the placebo effect with participants being much more likely to report positive change related to an intervention when they have a goal which is fulfilled through the confirmation of the placebo expectation (Geers, Weiland,

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Kosab, Landry & Helfer, 2005). Similarly it has been acknowledged that client expectancy within psychotherapy is an important factor when considering change in clinical symptoms (Joyce, Ogrodniczuk, Piper & McCallum, 2003). It is therefore possible that randomised controlled trials that claim to be measuring the impact of distant intercessory prayer on health are in actuality measuring strength of participant expectation regarding prayer.

Searching the available literature for systematic reviews regarding the relationship between intercessory prayer and physical health yielded one systematic review (Roberts, Ahmed & Hall, 2007). In addition the size of effect of intercessory prayer on physical health had also been studied using meta analysis (Hodge, 2007; Masters, Spielmans & Goodson, 2006). There have also been several review articles, for example studying the effects of intercessory prayer on family relationships (Day, 2003), physical health in college students (Lok, 2006), psychological well-being (Tloczynski & Fritzsch, 2002), student grades (Williams, 2002), smoking cessation (Herringhshaw, 2002) and pain management (Witter, 1997). No review articles were found exploring the relationship between intercessory prayer-related expectations and physical health outcome in randomised controlled trials.

3. Aims
This paper aimed to use systematic search methodology to review articles relating to the overall effectiveness, and the role of expectation of health improvement for prayer beneficiaries in randomised controlled trials of intercessory prayer in health care settings. Therefore the main aims were:

- To evaluate the extent to which intercessory prayer has been used as an adjunct to physical and mental health care.

- To appraise the extent to which randomised controlled trials have accounted for the role of participant expectancy with regard to intercessory prayer.

- To present an overview of the research findings and limitations in this area.

- To discuss the limitations which are inherent in randomised controlled trials studying distant intercessory prayer.

4. Method

Selection of Studies.

Several electronic databases were searched in order to identify relevant papers for inclusion within the literature review. The databases that were searched included Psych info 1887 – September 2007; Psych articles 1894 – September 2007; ISI Web of Science 1970 – September 2007, Embase 1980 – September 2007 and Medline 1950 – September 2007. The Dissertation Abstracts International and The Cochrane Library were also searched. Key words included "distant intercessory prayer", "prayer", "randomised controlled trial", "expectancy" and "health" and specified inclusion of key words within the title and/ or abstract. Articles written in English were used exclusively. The search was conducted in September 2007.

Inclusion and Exclusion Criteria

The search produced 46 papers, of which 15 were duplicates. Papers were included within the literature review if they met the following criteria:

- Studies identified participants who were associated with healthcare settings and who were receiving either physical or psychiatric interventions.

Participants with physical or mental health problems were included regardless of gender, race or age.

- Utilised randomised controlled trial design.

- Included outcome criteria that related to change in physical or psychiatric health symptoms following intercessory prayer.

Papers were excluded from the literature review if they:

- Failed to specify the use of distant intercessory prayer on behalf of someone with either physical or mental health problems, such as studies which specified the use of distant healing but did not explicitly mention distant intercessory prayer.

Paper Inclusion

Ten papers were identified which met the defined inclusion criteria. Of these ten papers, one study was excluded because whilst it included prayer within the intervention, it did not specifically mention that it included organised and committed distant intercessory prayer on behalf of someone with physical or mental health problems (Sicher, Targ, Moore & Smith, 1998).

Quality Control

The papers were assessed with reference to the reported results, and also in conjunction with a set of recommendations for use in evaluating the effectiveness of the reporting of randomised controlled trials (Moher, Schulz & Altman, 2001). This was viewed as an opportunity to enhance the systematic approach that was taken to reviewing the literature.

5. Results

The main findings from each of the nine studies included within the review are presented within Table 1. The review process highlighted articles, which included the use of intercessory prayer within physical and mental health settings. Eight studies included participants from inpatients settings (Aviles et al., 2001; Benson et al., 2006; Byrd, 1988; Cha, Wirth & Lobo, 2001; Conti, Matthews & Sireci, 2003; Harris et al., 1999; Leibovici, 2001; Matthews, Marlowe & MacNutt, 2000) and one study included participants who were outpatients (Mathai & Bourne, 2004). Four studies involved coronary care patients (Aviles et al., 2001; Benson et al., 2005; Byrd, 1988; Harris et al., 1999). One study focused on participants with Rheumatoid Arthritis (Matthews, Marlowe & MacNutt, 2000); one study focused on patients with bloodstream infections (Leibovici, 2001); one study focused on patients undergoing in-vitro fertilization (Cha, Wirth & Lobo, 2001); one study focused on patients with end-stage renal disease (Conti, Matthews & Sireci, 2003) and finally one study focusing on the treatment of child psychiatric disorders (Mathai & Bourne, 2004).

Design

Of the nine studies included, eight were randomised controlled trials (Aviles et al. 2001; Benson et al., 2006; Byrd, 1988; Cha, Wirth & Lobo, 2001; Conti, Matthews & Sireci, 2003; Harris et al., 1999; Leibovici, 2001; Mathai & Bourne, 2004). Matthews, Marlowe and MacNutt (2000), did not randomise the assignment of participants to groups, however it was included in the review because it was the only study to assess the religious beliefs of participants at baseline. Of the eight

randomised controlled trials, not one controlled for the possibility of prayer stemming from other sources, for example friends and family.

All the studies included within the review aimed to establish whether distant intercessory prayer could influence specific physical or psychological outcome measures. Of the eight studies that were randomised two studies found no significant difference between the control group and the prayer group as assessed by the specified outcome measures (Aviles et al., 2001; Mathai & Bourne, 2004). Of the remaining six studies, all found some significant difference in outcome measures between the prayer group and the control group. One study found a negative association between participants in the prayer group and health. Benson et al's (2006) results suggested that participants in the prayer group had significantly more cardiac bypass complications than those within the control group.

Table 1. Characteristics overview of papers included in the literature review.

6. Critique

Design

All nine of the studies reviewed specified participant inclusion and exclusion criteria. These criteria did not relate to the religious beliefs or expectations of the participants or intercessors. Of the seven RCTs only one study did not specify the randomisation technique used (Mathai & Bourne, 2004). None of the studies specified the sample size through use of power calculations or post-hoc analyses. Sample sizes appeared to be more opportunistic in approach, for example including all patients who whose blood stream infection was diagnosed within a specified time limit and specific location (Leibovici, 2001). All studies varied in the duration of intervention and whether there were follow-up criteria. Duration of intercessory prayer ranged from

very short term with prayer only taking place for the duration of the admission (Byrd, 1988; Harris *et al.*, 1999) to longer-term follow-up at six months (Aviles *et al.*, 2001). In addition only two studies specified the type of prayer that was required, and directed intercessors in what they should say whilst praying (Benson *et al.*, 2006; Harris *et al.*, 1999) There were also differences between the groups in terms of the amount of prayer given, and within some studies patients were prayed for by individuals (Byrd, 1988; Harris *et al.*, 1990) and in others by groups (Benson *et al.*, 2006). Whilst inclusion and exclusion criteria were generally well specified, the studies failed to explain the rationale for their choice of criteria or outcome measures, and this created difficulties in comparing results between studies.

Intercessor Expertise

Of the studies reviewed no clear attempts were made to set standards with regard to the expertise of the intercessors. For example within one study the intercessor was described only as "a person", with no mention made of his or her religious background or expertise (Leibovici, 1999). Other studies specified the use of Christian ministers, but did not specify denomination (Matthews, Marlowe & MacNutt, 2000). Others recruited from local religious groups (Aviles *et al.*, 2001), but were not clear about the inclusion and exclusion criteria for these groups. Of the nine studies reviewed three did not specify the religious affiliation of the intercessors (Aviles *et al.*, 2001; Leibovici, 1999; Mathai & Bourne, 2004), and the remaining six specified that the intercessors had Christian beliefs (Benson *et al.* 2005; Byrd, 1988; Cha, Wirth & Lobo, 2001; Conti, Matthews & Sireci, 2003; Harris *et al.*, 1999; Matthews, Marlow & MacNutt, 2000). Some studies countered the relevance of these observations through insisting that the religious expertise of the intercessors was

irrelevant since authors were attempting to measure the relationship between prayer and health, which does not necessarily relate to God's input (Harris *et al.*, 1999). Despite this, the majority of the studies reviewed, recruited religious intercessors and religious participants rather than atheists. This implies that religious belief and specifically belief in God's ability to respond to prayers was important. Therefore intercessory qualifications, religious affiliation and background should be stated and controlled for within the studies.

Measures/ Outcome Scales

There were differences between studies with regard to whether authors developed their own outcome measures (e.g. Byrd, 1988), or whether they used previously validated measures (e.g. Harris *et al.*, 1999). Apart from one study, which attempted to replicate research findings from a previous study (Harris *et al.*, 1999), none of the papers reviewed, explained why they adopted specific outcome measures, particular intercessors, specific patient clinical conditions or intercessory prayer wording. Comparing results between studies was complicated due to the use of differing outcome measures and control procedures. Of the studies reviewed, it was more feasible to compare results between studies when specific outcome measures were repeated. Harris *et al.* (1999) conducted a randomised double-blind trial and also replicated some of the measures and procedures used within the Byrd (1988) study, in addition they also used a validated scoring system (Mid American Heart Institute-Cardiac Care Unit Scoring System). Harris *et al.* (1999) were the only authors to repeat specific outcome measures from a previous study (Byrd, 1988) and utilise an RCT design, therefore the current paper continues by focussing on these findings in more detail.

Harris *et al.* (1999) investigated whether intercessory prayer would reduce the overall length of stay in a coronary care unit, and additionally if prayer would reduce the number of negative clinical events whilst participants were in hospital. Patients were unaware that the study was taking place, and consequently whether they were in the prayer or control group. Fifteen intercessors were used to implement interventions. Intercessors could be associated with any religious faith but had to comply with the statement "I believe in God. I believe that he is personal and is concerned with individual lives. I further believe that He is responsive to prayers made on behalf of the sick." (p. 2274). All participants received their usual health care and if they requested visits from the minister, this was granted. The prayer group received daily prayer for 28 days. The intercessors prayed for a "speedy recovery with no complications" (p. 2274).

Harris *et al.* (1999) did not specify the length of individual prayer sessions and no attempts were made to ensure that intercessors did not pray for participants within the control group. Several composite outcome measures were included and these were compared and contrasted with the overall measure of participant hospital length of stay. The outcome measure developed within the Byrd (1988) study was also utilised. The study found a significant improvement in health among the prayer group, however improvements were not consistent across measures. For example there was a significant difference on the overall global health outcome measure but this was not replicated in the individual constituents of the measure. There were no significant differences between the groups on the length of stay measure. This is relevant since the prayer asked for a "speedy recovery". Furthermore Harris *et al.* (1999) failed to replicate findings using Byrd's (1988) outcome measure. These results may relate to the failure to specify and justify outcome measures, which may have increased the

likelihood of making multiple unwarranted comparisons (Sloan & Ramakrishnan, 2006). This increases the chances of erroneously rejecting the null hypothesis and thereby making recommendations based on results that were due to chance rather than the effect of manipulation of the independent variable.

In contrast with the majority of studies included within the reviews, Conti *et al.* (2003) suggest that beliefs about the expectations of health benefits derived from prayer were of importance, however they failed to relate their expectancy findings to their results. Of the studies reviewed, five informed participants that they might be involved in intercessory prayer research, furthermore participants within these studies also expected to receive intercessory prayer from friends and family. For these reasons it might be important to assess for expectation of health benefits deriving from intercessory prayer within studies, however this was not investigated. This is concerning since it would be reasonable to hypothesise a relationship between perceived health benefits and prayer-related expectations.

Expectancy Controls

Roberts, Ahmed and Hall (2007) conducted a systematic literature review which examined the relationship between intercessory prayer and the alleviation of ill health. The primary aim of this review was to assess the rigour of the methodologies utilised within the studies reviewed, and thereby draw conclusions as to the effectiveness of intercessory prayer in the alleviation of ill health. Whilst the current paper was also interested in the reported efficacy of intercessory prayer, it also particularly highlighted issues of expectancy within studies and related results from studies to the prayer beneficiaries' health expectations.

Within the studies reviewed, there were no explicit measures assessing religious affiliation or expected prayer outcomes, however one study did include prayer expectancy issues within a pre-intervention examination (Matthews, Marlowe & MacNutt, 2000). This study investigated the effects of both direct and distant intercessory prayer on patients within a private rheumatology practice. Forty-four participants were recruited. The intervention group (N = 29) received an initial three-day direct prayer intervention and were followed up after 12 months. The control group (N = 15) received no prayer for the first six months and then they too received three days of direct prayer. Prior to the direct prayer, participants were asked about their beliefs regarding the importance of religion and also the "patients' level of expectancy for improvement in physical, emotional, spiritual and overall clinical status, as assessed by likert type scales." (p. 1179). Whilst these measures might have been informative in providing insight into the relationship between prayer expectancy and health outcomes, the results from these questions were not reported. Following the direct prayer phase of the study all patients were told that they might be involved in further intercessory prayer research and 23 participants from the 44 involved in the study received 6 months of indirect intercessory prayer, the other 11 participants did not receive distant prayer. The rationale for how participants were allocated to these groups was not explained.

The authors concluded that there were significant health improvements for participants, due to the direct prayer. There were no additional benefits accrued from indirect intercessory prayer. However this study recruited a small sample and confused the research design through administering direct prayer to both the control and the prayer group. They then failed to justify how they decided which participants to recruit to the distant intercessory prayer group or the control. Results may also be

interpreted as being directly related to prayer expectancy, thus participants were certain they were receiving direct prayer, and uncertain whether they received distant intercessory prayer. It could therefore be concluded that participants reported health benefits when they were certain that they had received prayer. Alternatively results could also be interpreted as relating to the amount of prayer that patients received. Distant intercessory prayer was likely to be greater overall, at the time that the patients were in hospital when friends and family might be more likely to pray for them. In contrast at the time of the distant intercessory phase participants had left hospital and therefore may have received relatively less distant intercessory prayer from friends and family. Thus rather than measure the difference between the effects of direct or distant intercessory prayer the study may have measured the effect of background prayer levels or the expectancy levels relating to prayer.

It is disappointing that of the studies reviewed the only study to access participants' beliefs about expectation (Matthews, Marlowe & MacNutt, 2000) did not include the findings within the results. The other four studies within which participants' were also aware that they might be involved in distant intercessory prayer research also failed to adequately account for expectancy. Even if it is conceded that prayer expectancy did not affect the independent variable because participants were not certain that they were being prayed for, or because they were unaware of the research, this does not account for the prayer-related expectancy attached to friends and family prayer. Whether studies reported results which did not reach significance (Aviles *et al.*, 2001; Matthews, Marlowe & MacNutt), or those which did (Benson *et al.*, 2006; Byrd, 1988; Cha, Wirth & Lobo, 2001; Conti, Matthews & Sireci, 2003; Harris *et al.*, 1999), they could conceivably be measuring

the degree of prayer-related expectancy which may be unrelated to the manipulation of the independent variable.

Rather than address both participant expectancy and additional distant intercessory prayer as potential confounding variables within the studies, these issues are minimised in importance. This is problematic because without appropriate controls, studies cannot be clear about which phenomenon they are measuring and therefore in this sense cannot claim to be randomised controlled trials as described within the recommendations for use in evaluating the effectiveness of the reporting of randomised controlled trials (Moher, Schulz & Altman, 2001). To truly control the confounding effects of additional prayer and participant expectation, illness would need to be concealed from both the participant and their families. This would be the only conceivable way of ensuring that participants received no additional prayer from either themselves or from friends and family. Clearly however this is not ethically viable and therefore researchers need to review whether RCTs are the most suitable methodology for examining the effect of distant intercessory prayer.

7. Discussion

A systematic review procedure was used to highlight nine studies, which examined the relationship between distant intercessory prayer, and physical or mental health. All studies included either inpatients or outpatients from healthcare settings. Studies included research in the fields of coronary heart disease, renal disease, IVF treatment, child psychiatric symptoms, rheumatoid arthritis and bloodstream infections. Of the studies reviewed eight were RCTs, and four of these were double-blind, randomised controlled trials. The remaining study was included because whilst it did not establish

randomisation, it did access baseline information regarding expectations levels of prayer-related health benefits.

Intercessory prayer as an adjunct to standard physical and mental health treatment programmes has shown significant effects across health care settings, and in this sense it suggests generalisability and apparent face validity. However the current review suggests that the content validity and reliability of the studies is extremely low, with studies not controlling for confounding variables and failing to define and coherently measure the effects of the manipulation of independent variables.

Intervention Effectiveness

Of the studies included within the review, the majority of RCTs found positive physical and psychological health benefits associated with the use of distant intercessory prayer as an adjunct to standard health care. However, all the studies included within the review were unclear about the mechanistic processes through which prayer may influence health outcome. Generally studies ignored the issue of identifying the active agents in any relationship between prayer and health. One exception was Harris *et al.* (1999), who suggested that they aimed to examine a phenomenon rather than a mechanism, therefore they were more interested in learning about whether there was a relationship between prayer and health rather than understanding how this process occurred. Harris *et al.* (1999) suggested that research, which clearly established a relationship between prayer and health, would enable future studies to investigate the causal mechanisms involved. Thus, whilst Harris *et al.* (1999) acknowledged lack of clarity within their study with regard the active mechanisms of prayer, they failed to resolve these issues. In light of the lack of reported understanding of the active mechanisms involved within distant intercessory

prayer and additionally the lack of content validity across studies, firm conclusions about the efficacy of prayer in healthcare settings cannot be made.

Implications for Clinical Practice

Research has suggested that there are high prevalence rates of religious coping within specific clinical populations (Koenig, 1998). In addition some patients request prayer to be included as an adjunct to standard medical interventions (Poloma & Pendleton, 1991). It seems important therefore that clinicians are well informed as to the potential costs and benefits of supporting direct or indirect intercessory prayer requests from clients within health settings. It has been well documented that there can be positive health benefits associated with private religious practices such as prayer (Koenig & Larson, 2001). However within the studies reviewed it was concerning to note that there was an inherent assumption that distant intercessory prayer, seemingly by virtue of its association with religious beliefs was automatically a benign intervention. Indeed of the studies reviewed, four were double-blind randomised controlled trials, and therefore participants were unaware that they were participating in research. Ethical approval was given on the basis that there was "no known risk" (Harris *et al.*, 1999). However since RCTs examining the effect of distant intercessory prayer are relatively recent this seems like a premature assumption. This is particularly concerning given Benson *et al*'s (2006) finding that patients in the intercessory prayer group had significantly more health complications than those in the control group. Within this study, despite significant results, the authors claimed that the worsening of cardiac symptoms for participants in the prayer group may be due to chance. Had these findings been generated within a double-

blind randomised controlled trial of a drug, it seems unlikely that the same conclusions would have been drawn.

If distant intercessory prayer does have an effect (whether positive or negative) on participants' health then it seems that the only ethically correct implication is to ensure that informed consent is obtained. However this solution is also not without complication, as this may lead to increased patient anxiety based on assumptions about how severe their symptoms must be in order to require prayer, and this expectancy may then also skew results. Indeed this reaction may have been key in understanding why such a large proportion of potential participants refused to participate in the Byrd (1988) study.

In order for RCTs to be conducted there must be an understanding of the potential active mechanisms within the independent variable and a hypothesis relating to the possibility of an effect stemming from the manipulation of the independent variable. If there is such a possibility then studies need to be clear in exactly what they are asking intercessors to pray for. Only two of the studies reviewed (Benson et al., 2006; Harris et al., 1999) actually specified what the intercessors were required to say during prayer. However these studies did not specify other variables, such as the length of time taken to pray, whether intercessors added extra requests, or whether intercessors also prayed for patients in the control group. When the independent variable is not clearly defined this is problematic for two practical and ethical reasons, firstly there is no way of controlling prayer interventions within and between studies, and secondly there is risk involved with interpretation of prayer, for example prayer for the alleviation of suffering could be interpreted as requesting death.

Implications for Future Research

As previously discussed there are several methodological and ethical flaws regarding the studies that have been reviewed. Methodological issues may be reduced through increasing the rigour and control of the measurement of prayer-related expectancy and the dependent and independent variables. For example research could better account for expectancy issues through taking baseline and follow-up measures of health related prayer expectation. It is less clear how the ethical issues could be addressed. Moreover whether there is any benefit in resolving these issues seems to relate to the key notion of the validity of the underlying theoretical framework, which underpins both the research hypotheses and design. All the studies reviewed were unclear about whether theological or scientific theory was central. For instance statistical tests and randomised controlled trials, which are based on the premise of understanding of predictive natural laws and norms, were used to examine phenomenon, which by definition stand outside these laws.

Leibovici (2001) demonstrated the impact that confusing theological and scientific theory underpinnings can have on the credibility of research findings. Leibovici (2001) utilised a randomised controlled trial to randomly assign patients to either a prayer or control group. The study aimed to measure the effects of intercessory prayer retrospectively in a group of 3393 patients with bloodstream infections. Outcome measures were described as mortality during hospital stay, length of stay in hospital and fever duration. One intercessor described as "a person" was requested to say a prayer for the prayer group who left hospital 4 – 10 years prior to the study. Participants within both groups then had their records checked to see if there were any significant health differences between the groups. Leibovici (2001) justified this design stating "we cannot assume apriori that time is linear as we perceive it, or that

God is limited by a linear time as we are" (p. 1450). This study demonstrates the tensions of using scientific methods, which are bound by predictable scientific principles to measure metaphysical phenomena, which are by definition unpredictable.

Masters (2005) argued that whilst God is metaphysical, science is physical, therefore natural processes are the domain of the sciences and the supernatural processes are the domain of theology. To confuse these theoretical underpinnings has led to a series of studies that struggle to make clear recommendations and conclusions because the research has not been based on solid scientific testable theoretical underpinnings. This therefore begs the question as to whether scientists should continue to put resources into studying the effects of distant intercessory prayer through use of RCTs or whether there are other more testable aspects of human religious experience that would both increase our understanding and stay true to the central tenets of scientific epistemology and methodology? For example quantitative or qualitative research designs could usefully explore the psychological effect that prayer for others has on the intercessor.

Table 1. Characteristics overview of papers included in the literature review.

Design	Reference and population	N, mean age and follow-up interval	Interventions	Outcomes	Comments
Double-blind, prospective, parallel group, randomised controlled trial.	Harris *et al.* (1999). Adults admitted to a coronary care unit.	N = 990. Mean age = 66. No follow-up.	Patients randomly assigned to either remote intercessory prayer group or control group	No significant difference between groups in length of hospital stay. Prayer group significantly less clinical complications than control group (p < 0.04).	Method of randomisation – medical record number. No quality criteria for intercessors. Ethical issues stemming from patients being unaware that they were prayed for. No control for prayer from other sources.

Design	Reference and population	N, mean age and follow-up interval	Interventions	Outcomes	Comments
Double blind, parallel group, randomised controlled trial.	Mathai & Bourne (2004). Children accessing child and adolescent mental health services.	N = 36. Mean age = 9. 3 month follow up.	Patients randomly assigned to either remote intercessory prayer group or control group	No significant difference in psychiatric symptoms (HoNOSCA measure) between prayer group and control group either initially or at follow up.	Method of randomisation not specified. Small sample size. Short follow up period. Ethical issues stemming from patients being unaware that they were prayed for. No control for prayer from other sources.

Design	Reference and population	N, mean age and follow-up interval	Interventions	Outcomes	Comments
Double blind, parallel group, randomised controlled trial.	Leibovici (2001). In patients with bloodstream infections.	N = 3393. Mean age = 47. No follow up	Patients randomly assigned to either remote intercessory prayer group or control group.	Significantly lower mortality (p < 0.04), length of hospital stay (p < 0.01) and duration of fever (p < 0.04) than the control group.	Method of randomisation – number generator. No follow up period. No quality criteria for intercessors. Ethical issues stemming from patients being unaware that they were prayed for. No control for prayer from other sources.

Design	Reference and population	N, mean age and follow-up interval	Interventions	Outcomes	Comments
Double-blind, parallel group, randomised controlled trial.	Cha, Wirth & Lobo (2001). Patients at an IVF treatment hospital in Korea.	N = 219. Mean age = 33. Follow-up time not specified.	Patients randomly assigned to either remote intercessory prayer group or control group.	Significantly more women in the prayer group had successful treatment than in the control group (p < 0.01).	Method of randomisation not specified. No quality criteria for intercessors. Ethical issues stemming from patients being unaware that they were prayed for. No control for prayer from other sources.

Design	Reference and population	N, mean age and follow-up interval	Interventions	Outcomes	Comments
Parallel group, randomised controlled trial.	Benson *et al.* (2006). Adult cardiac bypass patients.	N = 1802. Mean age = 64. 30 day follow-up.	Patients randomly assigned to one of three groups: received/ did not receive prayer after being told they might receive it, and received prayer after being told they would receive it.	Patients in the prayer groups had significantly more complications than those in the control group ($p < 0.03$). No significant differences between groups in mortality rates.	Method of randomisation – random block procedure. No control for prayer from other sources. At enrolment all participants expected that they would be prayed for by family members. Study therefore limited by expectation effects.

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Design	Reference and population	N, mean age and follow-up interval	Interventions	Outcomes	Comments
Parallel group, randomised controlled trial.	Byrd (1988). Adults admitted to a coronary care unit.	N= 393. Mean age = 59. No follow-up.	Patients randomly assigned to either remote intercessory prayer group or control group.	Patients in the prayer group had significantly lower symptom severity scores than the control group (p < 0.01).	Method of randomisation – computer generated list. No control for prayer from other sources. No baseline information taken about participants' religious expectations of prayer.

Design	Reference and population	N, mean age and follow-up interval	Interventions	Outcomes	Comments
Parallel group, controlled trial.	Matthews, Marlowe & MacNutt (2000). Patients with Rheumatoid Arthritis	N = 40. Mean age = 62. 1 year follow-up.	Patients informed of study and then assigned to either immediate, delayed or no remote intercessory prayer groups. All groups received direct prayer.	All participants showed significant improvement in the 10 physical outcome variables following the direct prayer intervention (p < 0.001). There were no additional benefits found in the group receiving additional distant intercessory prayer.	Randomisation not established. Both groups experienced direct prayer, which was found to be beneficial; therefore there was no "non prayer" control group. Authors did assess for degree of religious belief however this was not related to results.

Design	Reference and population	N, mean age and follow-up interval	Interventions	Outcomes	Comments
Parallel group, randomised controlled trial.	Conti *et al.* (2003). Patients with end-stage renal disease.	N = 95. Mean age not specified. No follow-up	Patients either expected to receive distant intercessory prayer (for period of admission) or visualisation. One group expected intervention but did not receive it.	Patients who expected to receive prayer reported better psychological outcome (BDI, BSI and BPPQ) than those expecting visualisation (p < and those receiving no treatment (p < 0.08).	Method of randomisation not specified. No assessment of religious beliefs. Ethical issues stemming from withholding promised intervention.

Design	Reference and population	N, mean age and follow-up interval	Interventions	Outcomes	Comments
Parallel group, randomised controlled trial	Aviles *et al.* (2001). Patients with cardiovascular disease.	N = 762. Mean age = 62. Six month follow-up	Patients randomly assigned to either a prayer group (prayer once per week for 26 weeks) or control group.	There were no significant health outcome measure differences -predefined physical measures re. health complications between patients in the intercessory prayer group and the control group.	Method of randomisation – interactive computer automated telephone system. No baseline information taken about participants' religious expectations of prayer. Large variation in amount of prayer between intercessors (range 1 – 100 patients).

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SECTION B: Research Report

An Exploration of Religious Coping in Carers of People with

Psychosis.

Chapter 1: Introduction

1.1 Chapter Overview

This chapter discusses the psychological and physical effects of caring for a family member with psychosis. Within this study psychosis refers to "functional psychoses", which include schizophrenia, affective psychosis and delusional disorders (see Fowler, Garety & Kuipers, 1995 for a review). It begins by linking this carer population to the theoretical concept of "caregiver burden", and critiques the utility of this concept. In continuing it conceptualises coping within a religious framework, and explores some of the literature relating to carers and religious coping. Finally the chapter identifies future research directions, and introduces the current study.

1.2 Caregiver Burden

The experience of caring for someone with psychosis can have a detrimental effect on the carer's physical and psychological well-being (Guiterrez-Maldonado, Caqueo-Urizar & Kavanagh, 2005). The degree to which caring responsibilities impact physically and psychologically varies depending on individual circumstances (Joyce, Leese, Kuipers, Szmuckler, Harris & Staples, 2003). Despite heterogeneity in caring experiences, there have been attempts to standardise and quantify caregiving experiences within a global measure of "caregiver burden" (Caqueo-Urizar & Gutierrez-Maldonado, 2006). Hoenig and Hamilton (1966) understood caregiver burden as two discrete categories, these were "objective burden", and "subjective burden". Objective burden referred to stressors that could be objectively confirmed and measured by an external source, for example hours of care required. In contrast subjective burden referred to the perceived negative emotions associated with the caregiver role.

Increased caregiver burden in individuals caring for someone with a diagnosis of schizophrenia has been linked with lack of choice in caring (Kuipers, Leff & Lam, 2002), specific symptomatology (Barrowclough, 2005), increased number of care recipient psychiatric admissions in the previous 3 years (Gutierrez-Maldonado *et al.*, 2005), living with the care recipient (Kuipers & Bebbington, 2005), older age of carer (Cook, Lefley, Pickett & Cohler, 1994) and lack of social support (Kuipers & Bebbington, 2005). However, it has been suggested that global measures of "caregiver burden" have oversimplified the caring process (Szmukler, 1996). For example it neglects the positive aspects of care giving, such as feelings of joy and satisfaction (Kuipers & Bebbington, 2005). Further limitations stem from a lack of definitional consensus (Kuipers & Bebbington, 2005), and difficulties in making independent distinctions between subjective and objective burden (Cuijpers & Stam, 2000). It is possible therefore, that the degree of psychological and physical impact derived from caring for someone with a psychosis depends on individual attributions relating to the appraisal of individual resources and coping capacities (Kuipers & Bebbington, 2005).

1.3 Coping as a Caregiver

Lazarus and Folkman (1984) defined three styles of coping. Firstly coping can be viewed as an active effort to change either the emotional reaction to the stressor (emotion-focused), or secondly, changing the stressor itself (problem-focused). Thirdly, coping can also be achieved through avoidance of the stressor. Literature has often linked avoidance to poorer psychological adjustment (Heiman, 2004). Alternatively, each of these approaches may have potential to promote psychological adjustment. This is dependent on the nature of the stressor and whether coping

strategies are used as long term or short term solutions. For example, a carer could avoid confronting challenging behaviour until they had the necessary resources to manage it effectively.

Knudson and Coyle (2002) explored the coping strategies utilised by parents who cared for a son or daughter diagnosed with schizophrenia. Results indicated that carers adjusted coping strategies depending on the symptom presentation of the care recipient. When the care recipient was presenting with positive symptoms, carers were more likely to use active problem-focused coping methods, for example trying to challenge delusions. In contrast when care recipients presented negative symptoms, for example withdrawal, carers were more likely to use emotion-focused coping strategies such as acceptance.

Within this study, avoidance-focused coping seemed to be used as a "last resort" when carers were clear that problem-focused, or emotion focussed efforts were not helpful. Knudson and Coyle (2002) suggested that for these carers avoidance could be protecting them from feelings of hopelessness that might be associated with failure to change a challenging situation. In this sense these carers appeared to have a range of coping strategies, which allowed them to be adaptive. Therefore it is possible that whilst individuals have a coping style that they may be more predisposed toward (trait-related), they are also capable of adapting coping strategies to meet new demands (state-related). Effective coping could therefore be viewed as being mediated by the cognitive appraisal of perceived control and appraisal of available internal and external coping resources.

As discussed above, there are often high levels of stress associated with caring for someone with psychosis. For people caring for someone with a chronic and fluctuating mental health problem like psychosis, the perceived stress associated with

caregiver responsibilities can change rapidly, particularly in response to acute psychotic episodes (Joyce *et al.*, 2003). As a result there is often a need for carers to be flexible and resourceful in their approach to coping. The following section will discuss how religious beliefs could be seen as a coping resource, and explores literature linking religious coping to psychological and physical health.

1.4 Religious Coping

Koenig *et al.* (1998) linked religious coping systems to improved psychological and physical health, however other research suggests religious beliefs can generate emotions of despair and resentment (Pargament, 1997). Therefore whilst literature suggests a relationship between health and religious coping systems, it is less specific about the nature of this relationship. Despite this, religious beliefs have been associated with the evaluation of life events, appraisal of available coping resources, utilisation of coping strategies and evaluation of coping outcome (Pargament, 1990).

Pargament, Kennell, Hathaway, Grevengoed, Newman and Jones (1988) proposed three styles of religious coping. The "self-directing" style placed emphasis for change with the individual. This style was associated with less traditional religiosity, and comparatively higher levels of personal agency and self esteem. In contrast a "deferring" style emphasised God as having control over life decisions. Finally, a "collaborative" style was characterised by a relationship that emphasised an equal partnership between the individual and God, where individuals worked with God to make decisions. This coping style was associated with a greater perception of self-control and higher self-esteem. Whilst both the "deferring" and "collaborative" styles emphasised "God control", the former seems to suggest manipulation of lives by God, whilst the latter emphasises active exchange and interaction.

Pargament *et al.* (1988) suggested that the "self directing" and "collaborative" coping styles may be more generally psychologically adaptive. In contrast, in situations where individuals perceive themselves to have less control, more passive "deferring" coping styles may be more functional. Pargament *et al.* (1988) provide a helpful framework for understanding the religious coping process. However, it is primarily a trait model of coping and does not account for more transient or situationally relevant coping strategies. It also focuses on how religious beliefs influence coping with significant life events, and neglects relatively less stressful daily stressors.

1.5 Religious Coping and Caring

As discussed above, religion can provide useful coping resources, however whilst religious coping has been linked to psychological and physical well-being for several clinical populations (Koenig & Larson, 2001), the carer population has been relatively neglected. Research suggests that carers of dementia patients have found religion to be a useful coping resource (Segall & Wykle, 1988), which has also been associated with sustained improved emotional health (Rabins, Fitting, Eastham & Zabora, 1990). However there is very little research linking religious coping with caring for someone with psychosis.

Rammohan, Rao and Subbakrishna (2002) explored the relationship between religious coping and psychological well-being in carers of people diagnosed with schizophrenia. 60 Hindu participants completed questionnaires relating to levels of caregiver burden, coping strategies and psychological well-being. "Religious coping" was not clearly defined, however it seemed to relate primarily to cognitive coping strategies. The results suggested that religious coping reduced distress and enabled

hope. Religious coping was also found to be more prevalent in response to deterioration in the psychological well-being of the care recipient. Therefore carers were more likely to use religious coping strategies at times of increased adversity.

Rammohan *et al.* (2002) concluded that caring responsibilities had often interrupted important life goals, for example completing education. In addition, carers who used active problem-focused coping strategies rather than denial were likely to have better psychological well-being. Results also suggested that in addition to religious coping, greater strength of religious belief rather than amount of religious behaviours seemed to relate to better psychological well-being. However, the study did not clarify relationships between religious beliefs, coping strategies and practices. This is significant since this is central to understanding how religious beliefs influence coping behaviours (James & Wells, 2003).

1.6 Current Study

Carers of people with severe and enduring mental health problems regularly provide vital emotional and financial support, and are often central in supporting service users within the community (Department of Health, 1999). Furthermore caring for someone with severe mental health problems increases the likelihood of physical and mental health problems in the carer population (Department of Health, 1999). It is therefore important to prioritise exploring sources of carer stress and identifying sources of available support, so that mental health services are better able to support carers and thereby also indirectly support service users (Kuipers & Bebbington, 2005).

Research has suggested positive psychological implications of religious coping systems in several client populations, including the elderly (Ellison & Levin, 1998),

palliative care patients (Johnson, Elbert-Avila & Tulsky, 2005), physical health patients (Musick, Traphagan, Koenig & Larson, 2000) and people coping with drug and alcohol issues (Gorsuch, 1995). However, to date there has only been one study exploring the relationship between religious beliefs and coping for carers of someone who has experienced psychosis (Rammohan *et al.*, 2002).

As discussed above, Rammohan *et al.* (2002) utilised a primarily quantitative methodology, which (along with the aforementioned methodological limitations) did not allow for the detailed exploration of individual religious beliefs and the effects that these beliefs had on the coping process. Therefore the current study aimed to explore in greater detail how carers of people with a psychosis have used religion in coping with their caring role. Specifically, the researcher was interested in the following research questions:

- How have carers experienced their caring role?

- How have carers used religious beliefs in supporting them with caring?

- How have carers made sense of psychosis within a religious frame of reference?

- How have carers interacted with mental health services, and how have mental health services responded to their religious beliefs?

Chapter 2: Methodology

2.1 Design

Henwood and Pidgeon (1992) suggest that qualitative methodologies are valuable for exposing meanings within previously unexplored research areas. The researcher therefore utilised a qualitative methodology due to the paucity of research in the area. Grounded theory was used to analyse data since it supported the exploratory nature of the research aims and also fitted with the researcher's epistemological position.

The author maintained a critical realist position throughout the research process. Reicher (2000) argued that grounded theory is necessarily realist because it assumes that language is a reflection of internal knowledge frameworks. Despite the emphasis on accessing core internal knowledge frameworks, this position does not negate the impact of social environment, for example in terms of influencing whether participants choose to share knowledge. Therefore the emphasis on both individual experience and social context requires grounded theory to be sensitive to the dynamic properties of process and change. From a critical realist position concepts of "objectivity" are replaced with those of "consistency of meaning", and in this sense the researcher made efforts to remain aware of her own bias and influence on the data (Madill, Jordan & Shirley, 2000). Therefore it is acknowledged that the researcher impacts on the data, however it is important that rigorous attempts are made to manage this impact and allow emerging themes to emanate from the data.

The Charmaz (2006) model of grounded theory was followed throughout the research process, in conjunction with a critical realist epistemology. This method was chosen because it emphasises researcher reflexivity and provides helpful method frameworks to enable reflexive awareness. Similarly it also emphasises useful methods to enhance data-theory coherence, for example memo writing and theoretical

sampling. Researcher reflexivity and data-theory coherence encourage researcher accountability and are central tenets within the critical realist epistemology.

2.2 Participants

Ten carers participated in the research (9 female, 1 male). All participants were members of carers' support groups. Participants were aged between 33 and 73 (mean of 52.1 years). The length of time as carers ranged from 2 years to 20 years (mean of 8.4 years). Participants were from a range of self-defined religious backgrounds (1 Spiritualist, 4 Evangelical Protestants, 3 Catholics, 1 Panenthiest[1] and 1 Hindu). Participants also had differing self-defined cultural backgrounds (6 White British, 1 Spanish, 1 African-Caribbean, 1 Czech, 1 Indian), and differing relationships with the care recipient (6 mothers, 1 daughter, 2 wives, 1 brother).

2.3 The Researcher

When the study was conducted the researcher was completing the final year of clinical psychology training. The researcher described herself as a Christian and her epistemological position as being critical realist. She was aware that her experiences of working with carers and service users with psychosis and also working within the context of the National Health Service influenced the research process. These experiences supported important initial assumptions about levels of carer support and the challenges of working with religious beliefs in clinical practice.

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[1] Belief that God is at the same time both part of the Universe and greater than it (Goring, 1992).

2.4 Procedure

A research proposal was submitted to, and approved by the Local Research Ethics Committee of the relevant NHS host Trusts prior to the commencement of the research (see Appendix B and Appendix C). In line with ethical guidelines no participants were contacted prior to receiving ethical approval. Following this University of Leicester ethical approval was also granted (see Appendix D).

2.4.1 Sampling Strategies

Participants were recruited via carers' support groups within the host Trusts. Carers' support group managers were approached as the "gate keepers" to the service. Managers and relevant staff were made aware of the inclusion criteria for the research (Appendix E). Carers' group managers placed an advertisement within their newsletters and information packs were made available. Packs included an invitation letter (Appendix F), participant information sheet (Appendix G) and a consent form (Appendix H). The researcher presented the research aims at group meetings where she encouraged carers to ask questions about the research. The groups provided support for carers of people across a spectrum of mental health difficulties, however, raising awareness of the inclusion criteria for the research allowed participants who specifically cared for someone with psychosis to opt into the research.

In addition to providing access to participants, support groups also had potential to provide emotional support for participants should this have been required at any point during the research process. Carers later made contact via post, email or telephone. Interviews were arranged with each of the carers who chose to participate in the research. Three groups out of the five approached participated in the study.

2.5 Data Collection

Whilst data for qualitative research can come from a variety of sources, the current study utilised semi-structured interviews. The researcher felt that this would be the most appropriate method of facilitating engagement with participants and their narratives, and also allowing flexibility within the research process.

A semi- structured interview schedule was constructed which aimed to explore the relevant research questions and facilitate adherence to topic areas (Henwood & Pidgeon, 1992). Discussions with colleagues, supervision, additional relevant reading and interviewer interests contributed to the initial construction of the interview schedule. However after interviewing had begun, theoretical sampling informed the continual adaptation interview schedules (see Appendix I). Within the interview schedule, questions were open ended, unless the researcher was checking conceptual understanding. Thus data gathering and data analysis ran concurrently within grounded theory methodology. For example, at the beginning of the data collection participants were asked general questions about how they used religious beliefs to support them in their role as a carer. These questions generated a theme of "locus of responsibility", therefore by the end of the data collection more specific questions about how coping was influenced by God's support or personal control were more relevant.

Participants received full details of the research procedure before choosing to opt into the study. Interviews took place at a setting convenient to the participant, including health centres, carers centre facilities, participant's homes and university accommodation. Participants were asked to sign a comprehensive consent form, which detailed each of the inclusion criteria. Throughout this, the researcher attempted to create a welcoming environment for the participants, with a view to

fostering engagement and open discussion (Mason, 2002). All interviews were tape recorded and lasted between 60 and 90 minutes. When the interview was completed, participants were asked if they would like a copy of the interview transcript and/or summary of research findings.

Following the interview the researcher recorded her initial thoughts and feelings about the interview in a reflexive journal. This facilitated reflection and recall.

Interviews were transcribed and coded by the researcher before subsequent interviews. All the carers who opted into the research were interviewed. However, during the analysis themes regarding carer protectiveness of care recipients emerged, and the researcher wondered whether this was gender specific. Therefore theoretical sampling informed the recruitment of a male participant.

Grounded theory suggests that interviewing should continue until "theoretical saturation" occurs (Charmaz, 2006). By the end of the interview process the researcher felt that the core category was saturated, and the main categories were approaching saturation, however the researcher stopped interviewing due to time constraints.

2.6 Data Analysis

The process of transcription influences the interpretation of data (O'Connell & Kowal, 1995). However, length of pauses and intonations were not included within the transcripts as they were not seen to be an essential component of grounded theory analysis (O'Connell & Kowal, 1995). Coding was divided into initial coding, focused coding, theoretical coding and memo writing (Charmaz, 2006). However the researcher utilised the constant comparative method and therefore worked

interchangeably between coding processes. Thus codes were revised and completed simultaneously.

2.6.1 Initial Coding

Initial coding allowed specific focus on words or lines of data that conveyed key ideas or actions. These codes allowed the researcher to compare incidents within interviews and between interviews. Tentative labels were attached to these "chunks" of data, and were often revised at later analytic stages. The tentative and flexible nature of the initial coding encouraged the researcher to remain open to emerging theoretical concepts and to reflect as accurately as possible the content of the transcripts (see Appendix J).

2.6.2 Focused Coding

Focused coding was more conceptual and directive than initial coding (see Appendix K). Analytic codes were assigned to data. This facilitated the development of hierarchical analytic categories, which were compared within and between transcripts. Distinctions were made between categories that reflected process and those, which reflected specific content.

2.6.3 Theoretical Coding

Theoretical coding allowed a better understanding of both the universal and the discrepant processes emerging within the data. Therefore categories, which had been previously fractured from the data, were developed into a more coherent story (Charmaz, 2006). This was often achieved through the process of memo writing.

2.6.4 Memo Writing

Charmaz (2006) emphasized the importance of memo writing in keeping the researcher grounded in the data, and in the generation of new theory. Memos contained thoughts about how categories related to each other and expanded on new concepts (see Appendix L). Therefore memo writing facilitated the generation of new theory through the constant comparison of data within and between data categories (Charmaz, 2006).

Appendices J, K and L have been chosen from the same interview, so that the reader can witness the analytic progression between initial coding (Appendix J), focused coding (Appendix K) and memo writing (Appendix L).

2.7 Methods Used to Enhance the Quality of Data

Henwood and Pidgeon (1992) suggest several methods to increase the quality of grounded theory method. In line with these recommendations, the researcher used memo writing and theoretical sampling to facilitate data-theory coherence. She also increased reflexivity through using a reflexive practice journal, which documented the research process and the researcher's reactions and assumptions within the data. Therefore both memo writing and the reflexive journal formed a documentation trail, which provided an account of the research process. The researcher also regularly attended a qualitative support group. This allowed inter-rater validation with regard to analysis of a selection of transcripts.

Chapter 3: Results Section

3.1 Chapter Overview

This section outlines findings stemming from analysis of ten interview transcripts. Results followed from the detailed coding process, described in the methodology section. Five main categories were identified and these are described with reference to the over arching core category. Charmaz (2006) suggests that grounded theory is useful in identifying processes within the data. Accordingly the chapter begins by describing how categories interrelate. The fluid nature of movement between categories is illustrated through presentation of the theoretical process model in Figure 1.

The researcher was interested in exploring how carers used religious beliefs in coping with their caring role. This section includes key quotes to illustrate categories, however references for further supporting quotes are included within Appendix M. The supporting quotes are identified within the text through brackets containing the participant number followed by the line number of the quote within the original transcript (e.g. P1/25).

According to grounded theory, categories and processes identified within analysis should be grounded in the data (Charmaz, 2006). Whilst the core category is more abstract than the main categories and sub categories, it too is grounded in the transcript data and represents a theme that was present in all interviews. The theory and processes presented in the process model are seen to constitute one possible understanding of the transcript data (Rennie, Phillips & Quartaro, 1988).

3.2 Process Model Illustrating how Carers used Religion as a Coping Strategy.

The Process Model was developed through a grounded theory analysis of the transcript data. It illustrates the interdependent relationships between each of the main categories and the core category, thereby identifying how participants used religion as a coping strategy within their caring role. The process model is fluid and participants moved within it depending on changing circumstances. Relationships between categories are illustrated within the process model diagram through use of arrows; arrows reflect process rather than causation. The model identifies both the stressors that participants contended with and the methods of coping. Carers used religion to support themselves when they found their lives to be unpredictable and to give meaning to times of suffering. They attributed responsibility for changed life circumstances to both themselves and to a higher force at different times, and this depended on the meaning that was attributed to stressful events. Participants either aligned or distanced mental health services from their understandings about God's will and this impacted on how they attributed responsibility to facilitate change. Carers also used a religious framework to prioritise role responsibilities, and this fluctuated depending on the unpredictability of life circumstances. Religious beliefs were also central in facilitating access to and creating barriers to support systems.

Figure 1: Theoretical process Model Illustrating How Carers Used Religious Beliefs in Coping

Negotiating Mental Health Services

Suffering as a Meaning Framework

Using Religion as a "Balancing Act"

Impact on Locus of Responsibility

Impact on Locus of Responsibility

Utilising Support Systems

Experiencing Unpredictability

Negotiating Role Responsibility
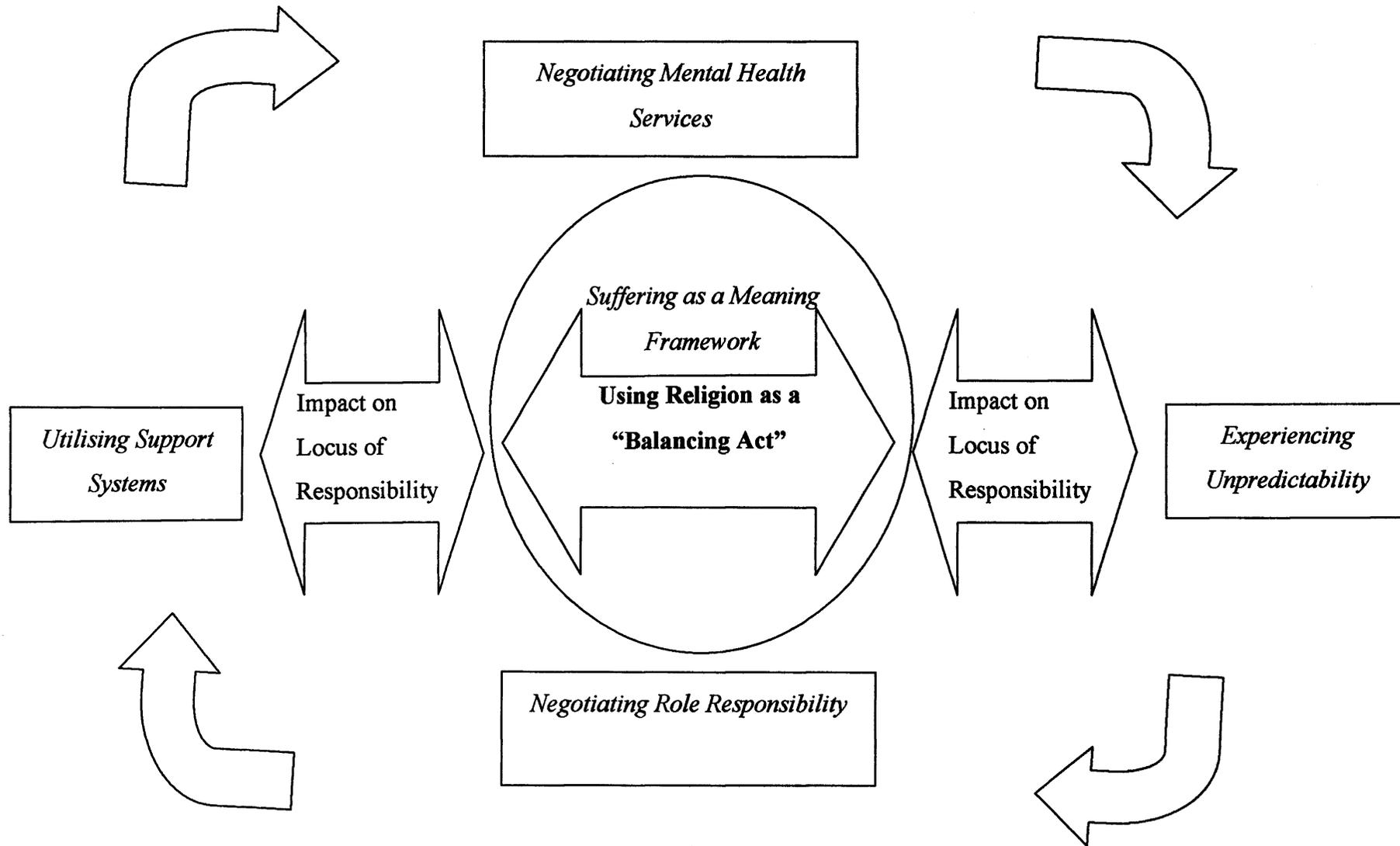
3.3 Core Category – Using Religion as a "Balancing Act"

This section examines the core category in more detail and seeks to conceptualise "Using Religion as a Balancing Act", with reference to each of the main categories.

All participants described using religious beliefs in negotiating and understanding their role as a carer. Carers used their religious beliefs to negotiate many of the difficulties that they associated with their caring role. Being a carer often involved having to adapt to managing the care recipient's psychosis with very little information (P4/441). Despite this, carers often found that they were expected to make significant decisions on behalf of the care recipient and the family system. Change in family relationships and role responsibilities when coupled with little knowledge of psychosis or mental health systems was seen to generate uncertainty and anxiety about the unpredictability of the future (P4/211). In addition carers often found that the support systems that they had accessed in the past were no longer appropriate (P6/295). Therefore in adapting to the role of a carer, there was a need to find support systems and beliefs that would provide understanding and meaning to both current and future difficulties. For some carers, the beginning of the caring journey was conceptualised as a crisis that led them to religion (P3/224). For other carers who were already religious before becoming a carer, religious beliefs were adapted to meet new demands (P4/220). For these participants religious beliefs served as a transitional coping strategy between life before being a carer and life afterwards.

The theoretical process model illustrates that participants viewed their religious beliefs as central to their core identity and as mediating important aspects of their lives. "Using Religion as a Balancing Act" refers to how carers coped with perceived extremes. Experiences were often perceived as being inherently good or bad, and this relates in part to the dichotomy of good and evil within religious doctrine. Religious

beliefs were therefore seen to provide a framework to make sense of the unpredictable and emotion-laden dichotomy of life events (P8/246). For instance religious beliefs were central in making sense of both positive and negative life events, for example understanding the presence or absence of acute psychotic episodes as relating to the presence or absence of demons (P2/136). Individual religious beliefs also provided a framework from which to facilitate active coping, for example taking personal responsibility for problem resolution or creating psychological distance from the problem. Thus, religious beliefs influenced choice of coping strategy and locus of responsibility.

All participants viewed the care recipient's psychosis as representing the "unknown". Carers perceived the psychosis as disrupting core life elements, such as employment (P1/15), social support and spontaneity (P5/572), family relationships (P4/218), and choice (P7/17). Initially they expected mental health services to be able to provide information as to the causes and cures of psychosis, however this was often not available (P8/259). When carers felt dissatisfied with mental health services religious beliefs helped to balance the unpredictability associated with caring for someone with psychosis through providing hope and reassurance that life would get better (P8/51). Participant often placed the responsibility for changing unpredictable situations with God, and this lessened the feelings of anxiety associated with unpredictability (P8/524):

"He is always there (God) *when I think that it can't get any worse and things do. And you don't think that things are going to get any better and they do, and things just, just as quickly as things get worse he can take it all away again as well and it's just amazing."*

Carers were often limited in where they could access social support due to the unpredictability of the psychosis and also the care recipient's views (P3/632). Religious beliefs influenced access to support, and impacted on how carers negotiated support systems (P6/273):

"My family, most of them are strict strict Catholics so I don't talk to them about my experiences because they are so strongly influenced by their religion, so I don't go there because we have arguments and don't talk. But my friends, I can choose my friends so they are more like open minded, more philosophical about it."

When carers' lives were particularly unpredictable, this had a direct impact on other key responsibilities. Religious beliefs allowed carers to balance priorities associated with role responsibilities. At times that were associated with great difficulties, participants often relied on their religious beliefs and behaviours such as prayer (P4/239). The ability to access a supportive religious belief framework was seen to provide some "sanctuary" from the uncertainty and anxiety (P10/622):

"I find it very difficult if there are lots and lots of pulls on me, I understand entirely what Ghandi said one day "I have got a very busy day today I will have to meditate for twice as long this morning.""

Carers understood suffering with reference to their religious beliefs (P5/274). They used religious beliefs as a gauge to assess who should have responsibility to change difficult situations. Insight into the meaning of suffering allowed many carers to have a relationship with God which emphasised joint responsibility for change (P10/35). Experiences were often categorised as being inherently negative, as such

religious beliefs helped carers make sense of adversity and this was often managed

through associating current adversity with promised future insight (P9/52):

> *"I think I wouldn't say I wanted adversity to the extent that I have had it, but I*
>
> *do believe that everybody should have some sense of adversity, sort of some*
>
> *aspect of it because I don't think you are aware of just how wonderful life is if*
>
> *you don't know how rubbish it can be."*

Generally carers found negotiating mental health services to be challenging for

both themselves and the care recipient (P7/43). Carers understood mental health

services through either distancing or aligning them with their religious beliefs, and

this provided meaning to their experiences. The process of either aligning or

distancing services from God, impacted on the degree of responsibility for change.

This carer described feelings of disillusionment regarding the ability for services to

help and placed the responsibility to change challenging situations with God (P8/205):

> *"I should remember all the time that I have got God in my life and you know the*
>
> *things that they* (services) *can't humanly deal with, and they can't be*
>
> *everywhere at the same time, God is there all the time and he can sort it."*

3.4 In Depth Exploration of Main Categories

Each main category comprised a number of subordinate categories, which gave

contextual meaning and clarity to the main categories. The remainder of the section is

devoted to examining these categories in more detail. Diagrammatic representations

of each main category are provided.

3.4.1 Main Category - Experiencing Unpredictability

Carers spoke of psychosis as symbolising unpredictable and dramatic change for which they felt very unprepared (P5/18):

> "It's totally unpredictable, and it's that unpredictability that is so difficult to cope with. With a long term illness, whilst you have minor eruptions and minor stresses and minor times of not knowing quite what to do, with this it's so volatile, it comes out the blue and it shows itself in such strange ways sometimes, ways that you have never experienced before."

They identified unpredictability with the psychosis rather than with the care recipient and this allowed carers to be angry and resentful of the psychotic symptoms without placing blame with the care recipient (P8/117). The different aspects of "experiencing unpredictability" are presented in Figure 2.

Figure 2: Diagram Illustrating "Experiencing Unpredictability"
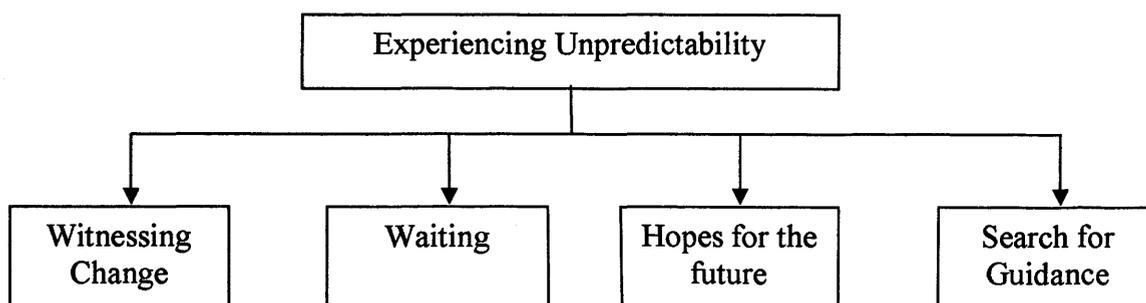
3.4.1.1 Sub Category - Witnessing Change

Carers witnessed change in the person that they cared for and all participants attributed change to the psychosis rather than the care recipient. Carers noticed that care recipients changed according to whom they were interacting with (P4/179). The

change that carers witnessed in the care recipients' personalities often made it difficult to relate to, and communicate with the person they cared for. This change was noticed at times of acute psychotic episodes and also on a more permanent basis (P6/232):

> *"He is just a completely different person and I am his enemy at that moment, all of the time. It's strange but he becomes very abusive psychologically in that moment and I always question is this the real (husband). Is what he is actually saying the truth, or is the truth what he is saying when he is well?"*

3.4.1.2 Sub Category - Waiting

Carers experienced waiting for change in psychotic symptom presentations to be very anxiety-provoking. Anxiety about the future was generated when care-recipients were well in case they relapsed, and anxiety was also generated in relation to acute psychotic episodes (P6/246). At these times carers struggled to manage feelings of wanting care recipients to regain independence and also wanting to protect them from danger (P2/262). Carers found strength in the knowledge that they had a relationship with God to support them, however living with constant uncertainty was experienced as being extremely stressful (P6/322):

> *"When he has these relapses, you think oh I will get used to it. But you don't and every time you feel more tired of it and I'm like I cannot cope anymore, but then it's fine and I'm strong again and I will cope, but when it comes to that moment I feel just so drained."*

3.4.1.3 Sub Category - Hopes for the Future

Hope for the future was generated through religious faith (P8/51) and perceived improvements in the well-being of the care recipient. Carers were alert to changes in the care-giving relationship, with positive changes requiring adaptation of the caring role (P9/58) but also as representing a more positive future. Despite recognition of improvement, participants were still mindful of loss in the quality of relationship when compared with the care recipient before they had psychosis (P9/621):

> "I have still to care for him, to remind him of his medication and things, but it's more of a husband and wife, than it is mother and son situation which it has been like."

For many therefore the ultimate hope was that the care recipient would always be well and that life would return to how it was before the psychosis (P8/261).

3.4.1.4 Sub Category - Search for Guidance

Participants actively engaged in seeking guidance for coping with the unpredictability of psychosis. However, many carers felt that mental health systems could not provide the answers they required (P8/258):

> "The mental health team have told me that probably, they won't commit themselves because they can't and I understand that nobody knows enough about the illness yet to know whether he is always going to always suffer from it."

The lack of hope generated from mental health services amplified the need to feel that participants were supported in their relationship with God. This relationship was

crucial in placing some responsibility with God for supporting carers in coping with current difficulties and in preparing participants for future adversity (P8/289). Therefore religious beliefs could provide a sense of hope, which allowed carers to maintain strength (P4/514):

"Reassurance that God is there, that God hasn't forgotten me, that God is still watching over us and that God is going to help us through life in whatever way, either to come to terms with it for the long term, to come to terms with it and give us the strength to carry on and deal with it as well as one should."

In contrast at other times carers felt that their religious beliefs did not provide them with the reassurance and hope that they required, and this could lead to anger with God (P4/259):

"Well I felt that I was completely forgotten and that I was very annoyed, absolutely annoyed with God. At the same time I said how could you do this? When something happens it is bad enough and you pray that things will get better and then it got worse and you pray again and it gets worse and it's what are you doing? You know what you are doing. What are you trying to do? I cannot take much more. You have to stop because there is only so much I can take."

3.4.2 Main Category - Utilising Support Systems

Whilst the unpredictable nature of the psychosis and the caring role restricted available support systems, carers accessed support from both religious and non-religious sources. This section explores the psychological buffers and barriers that emanated from these systems and the ways in which carers used their religious beliefs

to negotiate them. The different aspects of utilising support systems are presented in Figure 3.

Figure 3: Diagram illustrating "Utilising Support Systems"

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                    │  Utilising Support Systems  │
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              │                  │                      │
              ▼                  ▼                      ▼
      ┌──────────────┐   ┌──────────────┐   ┌─────────────────────────┐
      │   Support    │   │  Religious   │   │      Individual         │
      │   Groups     │   │ Institutions │   │  Information Seeking    │
      └──────────────┘   └──────────────┘   └─────────────────────────┘
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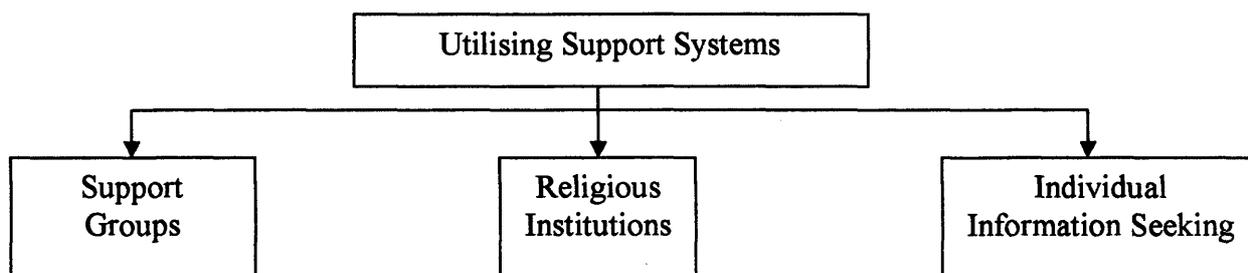
3.4.2.1 Sub Category – Support Groups

When carers could access support groups, many found this a liberating experience, which facilitated mutual exchange of challenging experiences (P4/475):

"It's like a release valve, but the important thing for my well being."

In contrast, other participants felt that a problem-focused approach was unhelpful (P5/452). Groups provided support at times of crisis (P3/308), and served as a source of information, however this was sometimes felt to be overwhelming or inadequate (P8/745). Some carers found listening to the experiences of other carers to be frightening, and this emphasised the need for information to be time appropriate for carers and their families (P4/455):

"It was very interesting, at times very frightening for me, because its oh my God, but of course you are seeing not just your case but you are seeing the whole spectrum of what could happen and it was frightening."

Whilst all participants both accessed support groups and also used religious beliefs to support them in their coping roles, many felt that it was inappropriate to mention their religious beliefs within the group and felt silenced (P4/500):

"I didn't know whether anybody had any spiritual needs because nobody would talk about it."

3.4.2.2 Sub Category – Religious Institutions

Many carers viewed their religious institution as a family, where they felt a personal and spiritual connection to other people, and this was seen as being extremely important in providing social and spiritual support (P2/337):

"It's like an extended family, we are brethren, we are one in the Lord, we think the same, we pray the same and we believe the same, and we look after one another, is what we try to do, if you are sick we try to help."

Religious institutions provided an important context for spiritual revelations (P3/288), and could be a source of respite from caring duties (P3/906). However sometimes religious support was perceived as unhelpful, for example this carer described the anger she felt towards members of her faith community because they had visited her daughter whilst she was on section (P3/867):

"They didn't ask if they could go and they didn't ask the staff if they could go in. They just barged in and started praying round the bed rebuking the devil again and she (daughter) just went crazy."

Whilst some carers felt that they could openly discuss their caring role within their religious institutions, several other carers did not find this possible. This could be

challenging for carers who wanted to access support and understanding but felt lost and alone within their religious institution (P4/762):

" *I think that in the main churches, especially if they are big that that is lost (support), you have got to look for it yourself, it doesn't come to you.* "

3.4.2.3 Sub Category – Individual Information Seeking

All participants spoke about the drive to acquire more information about psychosis, especially soon after diagnosis (P1/209). Whilst some carers perceived knowledge about psychosis to be empowering, others found that their religious beliefs were challenged. This participant described her religious beliefs changing following completion of a psychology degree (P6/105):

"I think that even before the degree I was more ... I probably questioned less my beliefs or questioned less who actually influenced that, whereas now I question that more but still I have it as a background, and it is a safety net."

3.4.3 Main Category – Negotiating Role Responsibility

Depending on attributions made regarding life unpredictability and access to support systems, carers fluctuated in how they identified with and negotiated competing role responsibilities. This section explores the main category which identifies carer role responsibilities and considers how carers used their religious beliefs to balance competing role expectations. The different aspects of negotiating role responsibility are presented in Figure 4.

Figure 4: Diagram Illustrating "Negotiating Role Responsibility"

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                    ┌─────────────────────────────────┐
                    │  Negotiating Role Responsibility │
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             ┌──────────────┼──────────────────────────┐
             ▼              ▼                           ▼
   ┌──────────────────┐  ┌──────────────────┐  ┌──────────────────┐
   │ Family Role      │  │ Direct Care      │  │ Employment       │
   │ Responsibility   │  │ Responsibility   │  │ Responsibility   │
   └──────────────────┘  └──────────────────┘  └──────────────────┘
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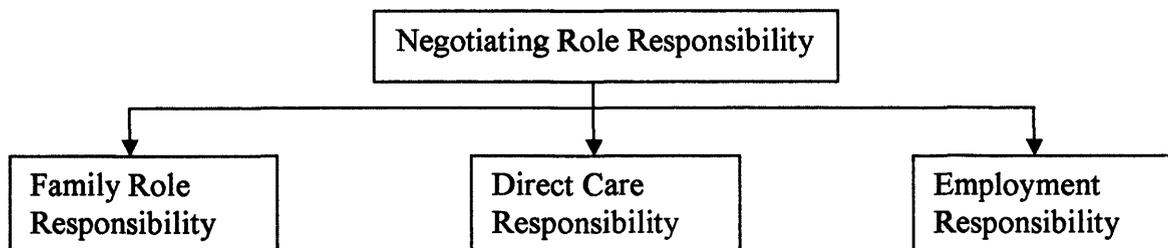
Identification with the caring role often resulted in a change in the nature of the relationship with the care recipient. This change was associated with the illness progression (P9/206), and consequently carers fluctuated over time in how much they identified with the caring role (P3/1006). Carers spent time reflecting how they had come to understand both psychosis and their capacity to make a difference in the life of the person that they cared for (P6/307):

> *"So I thought, OK I can help him* (husband), *and love is mad basically, you are blind when you are in love, so I just made the decision that, to be with him and now I think that I was a bit naive because you just cannot help, you can help to a certain extent but you cannot cure the person."*

3.4.3.1 Sub Category – Family Role Responsibility

Carers attempted to meet the needs of both the care recipient and other family members, and at times this resulted in feeling a tension between direct caring responsibilities and the needs of the wider family (P9/34). Tensions in negotiating caring responsibilities and family responsibilities often had a detrimental effect on relationships, with carers feeling torn between the stress associated with caring for someone with psychosis and also the drive to protect them and advocate for them (P1/774):

"I was going to leave the house and I was going to take my son with me, and go and live in a flat. I didn't get quite that far. And we used to go out with each other (son) and I didn't want to be with him, I just don't know, I couldn't stick it at all."

The tension that carers experienced in attempting to meet multiple family demands could result in guilt (P4/599) and conflict, and at these times religious beliefs could be central in promoting forgiveness. (P9/282):

"I got to the point where I really hated her (sister), and now I just feel sorry for her, that's what my religion has enabled me to do."

In contrast religious beliefs could also be the cause of conflict, particularly when the carers religious beliefs were different from the care recipient (P8/75) or the wider family system (P7/364):

"My husband left me because of my religion."

3.4.3.2 Sub Category – Direct Care Responsibility

The unpredictable nature of the psychosis resulted in carers experiencing a tension between protecting the care recipient and promoting independence (P4/180):

"Obviously he thought that home was a safe place, but at the same time he don't want to be here, he wanted to be in the world with all the others. We made it as pleasant for him as we could, we never say things that ...we were very careful what we said and always cheerful."

Religious beliefs helped to provide clarity for carers in the process of balancing protection and the promotion of independence (P2/58).

> *"I said would you like to go there? and he said he's not sure, but I talked him into it and the church pastor and the people in the church talked him into it, telling him that it's a privilege."*

On some occasions participants took an active role in trying to reduce the impact of the psychosis (P1/491), and used core religious principles such as unconditional love to inform the caring process (P5/225). At other times carers took a more passive approach and waited for God to provide support (P8/310).

3.4.3.3 Sub Category – Employment Responsibility

Some participants had to stop working when they became carers and this had a profound emotional impact (P3/73). Others found it difficult to balance employment and carer responsibilities, and this impacted on access to support resources that had previously been available before participants became involved in caring (P6/4):

> *"I was doing both things, like caring for him and at the same time doing my degree which was quite difficult, it was very stressful and demanding on both elements."*

Employment responsibilities also resulted in less available access to religious support systems (P3/246):

> *"I'm doing the shifts, I'm not heavily involved in the church because with working Sundays and often I'm working when there is things on."*

For carers who had stopped working in order to care, the ability to return to work was viewed as evidence of improved health in the care recipient, and therefore as a source of hope for the future (P9/629).

In contrast other carers utilised skills acquired within their caring roles in their employment role (P1/73).

3.4.4 Main Category - Suffering as a Meaning Framework

Participants viewed challenging caring experiences within a framework of meaningful suffering. This framework provided both context and purpose (P10/348) to stressful experiences and consequently facilitated hope and strength to cope with both current and future caring responsibilities (P9/165):

> "Suffering is necessary not just to make you better but to let you appreciate life."

The different aspects of understanding suffering as a meaning framework are illustrated in Figure 5.

Figure 5: Diagram Illustrating "Suffering as a Meaning Framework"

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                    │  Suffering as a Meaning Framework │
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        ┌──────────────────┬──────────────┬────────────────────┐
        ▼                  ▼              ▼                    ▼
┌──────────────┐  ┌──────────────┐  ┌──────────────┐  ┌──────────────┐
│  Cause of    │  │  Perspective │  │  Catalyst for│  │    Trial     │
│  psychosis   │  │  on others   │  │  strength    │  │              │
└──────────────┘  └──────────────┘  └──────────────┘  └──────────────┘
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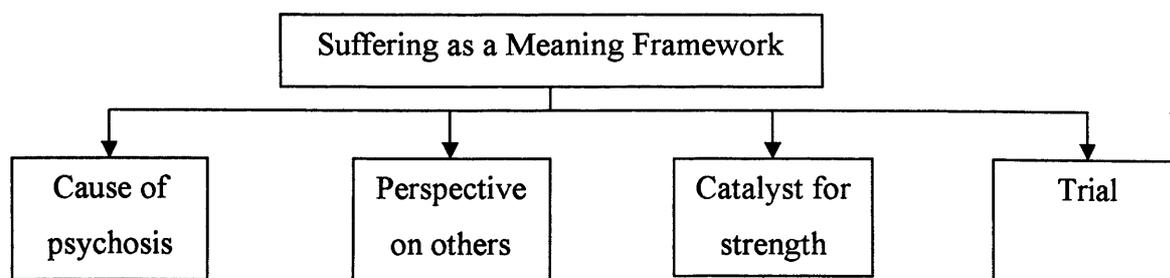
3.4.4.1 Sub Category – Cause of Psychosis

Suffering was often perceived as relating to the cause of psychosis. Stress resulting from the environment was seen as a primary cause. However carers differed in whether they perceived environmental suffering to be the primary cause (P4/136), or whether they perceived religious suffering to be the primary cause of the psychosis (P2/167):

> *"He can be very nice to me sometimes, and sometime he just ... some time I am afraid in his presence you know? This is how the demon in him present itself."*

3.4.4.2 Sub Category – Perspective on Others

Religious beliefs facilitated understanding of suffering and therefore allowed distinctions to be made between "real beliefs" and those that were perceived as being part of the symptomatology of psychosis (P5/383). This understanding provided a framework from which carers could reason with the care recipient. However when carers held differing understandings of the meaning of suffering from the care recipient, this created additional challenges, including a stunting of emotional expression and coping (P9/203).

Importantly a religious framework for suffering also allowed carers to make sense of their own experiences and conceptualise them as meaningful. A religious understanding of suffering allowed participants to make sense of the experiences of other non-religious carers, which engendered a comparative model of coping and also feelings of sympathy for those without religious beliefs (P9/170):

> *"I think they see life in black and white and I see it in Technicolor."*

3.4.4.3 Sub Category – Catalyst for Strength

Suffering was viewed as a process, which had the potential to increase strength. Some carers attributed the strength to personal resources (P10/328), whilst other carers attributed it to God (P8/450);

> *"I say oh thank you God, I know that you were sorting that out it was nothing to do with me, I know you put that right because I started it off all wrong but you have corrected it."*

3.4.4.4 Sub Category – Suffering as a Trial

Some carers understood suffering as being part of a God-given trial. This suggested a greater meaning and purpose to suffering that would be apparent in the future (P8/557):

> *"I have got to believe that whatever I am going through now, there will be a reason for it, and it will be well worth it."*

Participants were able to identify events or thoughts that acted as proof of suffering being part of a trial (P9/139). However this knowledge also engendered some anxieties about the future, and resentment that the suffering may continue. Perceiving suffering to be part of a God-given trial could be particularly distressing if coupled with a lack of responsibility to control difficult circumstances (P5/284):

> *"Without doubt it's a trial, it's the worst trial I think I have ever been through, I'm not sure how it will all come out in the end, none of us can see that."*

In contrast when participants had more equal working partnerships with God then there was potential to negotiate the amount of suffering that would happen in the future (P4/610):

> "I like to think that what I have gone through, I might be prepared now and stronger, but I hope that when I talk to God, I said to him well remember I am not too strong!"

3.4.5 Main Category – Negotiating Mental Health Service Provision

Negotiating the mental health system was a challenging process and many carers were unprepared for this, particularly as previous experiences of health systems related to brief relatively simple physical complaints (P3/76):

> "You do believe that with this help and with this hospital you should be alright, maybe a few pills."

Negotiating mental health service provision was often experienced as being particularly challenging when carers believed that mental health professionals were not accepting of their religious beliefs (P6/131), and that they were blamed by services for causing the psychosis (P2/198). Therefore carers either distanced mental health services from God or aligned them with God, and this allowed them to make sense and negotiate with services.

The different aspects of negotiating mental health services are illustrated in Figure 6.

Figure 6: Diagram Illustrating "Negotiating Mental Health Services"
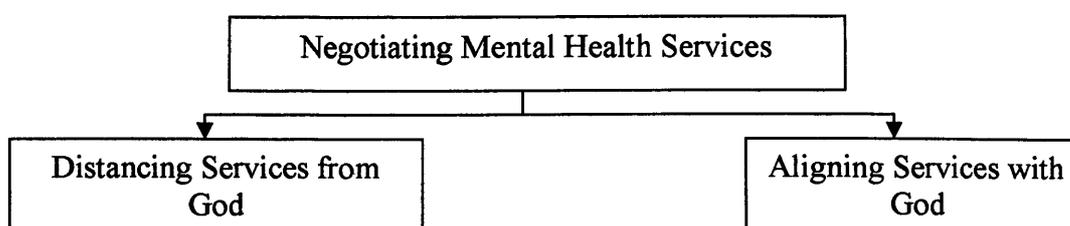
3.4.5.1 Sub Category – Distancing Services from God

Participants often felt dissatisfied with services, both in terms of the service provision and in their personal relationships with mental health professionals. Carers understood these difficulties within their religious belief framework. This process helped carers to make sense of personal relationship difficulties with mental health professionals, and also cope with issues of blame that may have been associated with the cause of the psychosis (P5/359):

> *"My dear if you are a religious nutter it has contributed to your son's psychosis and you aren't quite the ticket, you are weak and you have to depend on some archaic faith that should have been dead and buried years ago but because of your weakness of mind and character and personality, you need to rely on a religious faith, poor you, no wonder your son is suffering the way he is. Yes, that's how I feel."*

The divide between carers and services resulted had potential to result in disagreements regarding the treatment for psychosis (P2/363):

> *"Jesus command demons to come out of people and many stories in the bible that would help them. So I think that this little branch of psychiatry need to expand to such things."*

Disagreements regarding the cause and cure for psychosis facilitated strength to advocate for service users regarding a number of issues, but particularly medication (P8/726).

Eventually if carers did not feel that their beliefs were respected by services, this facilitated disengagement and feelings of hopelessness (P2/634):

> *"I keep mentioning all these things, it's just like banging my head against a wall really. I don't even like going to their (services) meetings really because it's just recycling things all the time, nobody listening."*

3.4.5.3 Sub Category – Aligning Services with God

Whilst many carers felt dissatisfied with services, others reported receiving satisfactory support from mental health services. When they had positive experiences with mental health professionals they were more likely to view these individuals as being aligned with God's will. This carer described her experiences of services introducing the family to religion (P3/223):

> *"He (psychiatrist) was ever such a nice man, lovely and he said "have you ever thought of having a faith, have you ever thought of God? Maybe you could turn to God and that would help you?""*

For carers that aligned mental health services with God this generated strength and motivation to continue positive relationships with services (P8/755):

> *"I have to believe that God is working amongst the mental health team, because otherwise I would be loathed to have anything to do with them."*

In summary, this section has presented a detailed account of the data generated from grounded theory analysis of ten interviews. The analysis reveals data that demonstrate both discrete categories of meaning and also process relationships

between categories. The following section will continue to situate the findings from the current study within the context of existing literature and theory.

Chapter 4: Discussion

4.1 Chapter Overview

This qualitative research study aimed to explore how ten carers of people with psychosis used religious beliefs in helping them cope with their caring role. The results suggested a complex coping process with religious beliefs contributing to an understanding of the cause of psychosis and also providing a flexible and adaptive coping system. This chapter discusses how findings relate to research aims and the wider literature. It also alludes to the clinical implications of the study. Finally it considers methodological limitations and emphasises future research opportunities.

4.2. How did Carers use their Religious Beliefs in Supporting them with Caring?

4.2.1 The Core Category: "Religion as a Balancing Act"

Within the current study religious beliefs provided a framework of understanding, which helped to make sense of unpredictable times and provided motivation for hope and strength to continue caring. Carers related both positive and negative experiences to their religious beliefs, with a religious frame of reference mediating the relationship between events, coping strategies and sense of control. The degree to which carers believed they could influence challenging situations related to how they attributed responsibility for changing these situations. This was also dependent on multiple factors relating to previous experiences of problem resolution and the impact of other support systems. Participants' coping could therefore be viewed on a continuum of responsibility to change challenging life circumstances. At one end of the continuum carers believed that God was a source of guidance but that generally they had personal control, in contrast at the other end of the continuum carers devolved all personal control to God.

Within the current study carers used religious coping strategies in managing adversity and balancing perspectives on the personal impact of caring. These results echo research, which has suggested that carers of people with schizophrenia adapt coping strategies in response to the care recipient's illness progression and coping resource availability (Knudson & Coyle, 2002). Therefore participants within this study utilised "context dynamic" coping strategies, with coping changing over time and being situation dependent (Folkman & Moskowitz, 2004). This study therefore builds on models of coping which have identified "predispositional" religious coping styles (Pargament, 1997), firstly by suggesting that people may utilise more than one religious coping style, and secondly through suggesting processes which may influence the transition between one coping style and another.

4.2.2 The Theoretical Process Model

The core category, "using religion as a balancing act", was embedded within the theoretical process model (Figure 1). This model suggests one way of understanding some of the contributing factors which influenced how carers used religious beliefs in coping with their caring role. Carers understood one challenge of caring to be managing the unpredictability of the care recipient's mental health presentation. This was important because it increased anxiety and concern for the well-being of the care recipient but also because it disrupted other areas of life. At these times carers increased their commitment to their caring role, and therefore struggled to maintain other responsibilities, for example employment and support systems. Thus for many, the caring experience was punctuated with episodes of increased anxiety and concurrent reduction in social support systems. Environments which promote little opportunity for personal control and high levels of demand have been linked with "burnout" (Maslach, Schaufeli, & Leiter, 2001). The concept of burnout appears

similar to that of caregiver burden with antecedents to both, relating to lack of autonomy, high levels of anxiety and low levels of social support (Cheng, 2006). Therefore the current study suggests that the mental health of carers may be adversely affected if they are exposed to unpredictable care giving environments and inadequate support.

Episodes of acute need were important in influencing beliefs about adequacy of mental health service input. At times of acute need, carers relied on their religious beliefs to help them cope, often placing extra emphasis on God's responsibility to help resolve difficult situations. Therefore if they perceived mental health services to be disrespectful of their religious coping beliefs this reduced the likelihood of positive working relationships. In summary therefore, how carers interacted with external support services, coping systems and their personal view of their own role responsibility was dependent on individual religious belief systems, which were both time and context dependent.

4.3 How did Carers Experience Caring?
4.3.1 Experiencing Unpredictability

Witnessing psychosis-related changes in care recipients was frightening for carers, and this exacerbated beliefs that the care recipient's core identity had been altered since the onset of psychosis. Changes were experienced as being unpredictable with little observed warning as to personality or behavioural shifts. Research suggests that carers often find it more difficult to cope with negative symptoms (for example withdrawal), than positive symptoms (for example hallucinations) (Provencher & Mueser, 1997). However, current participants did not make this distinction and found both negative and positive symptoms to be stressful. Some carers attributed change to either God or Satan, and this allowed for the integration of frightening experiences

into an existing knowledge framework. This process also facilitated the reattribution of blame from the care recipient to a higher force. The distancing of the illness presentation from the person also facilitated maintenance of relationships when care recipients expressed negative or challenging behaviour toward the carer (Knudson & Coyle, 2000). This is important because carer ability to make person-illness distinctions has been related to lower distress levels, higher levels of self-esteem and reduced relapse likelihood in care-recipients (Barrowclough & Hooley, 2003).

4.3.2 Emotional Adjustment

The degree to which carers required support related to the mental illness presentation of the care recipient. Therefore participants were constantly required to adjust emotionally to changing care requirements, and to ideas about the future of the care-giving journey. Karp and Tanarugsachock (2000) suggest that carers progress through emotional stages beginning with the denial of the severity of the care recipient's illness and ending with acceptance. Whilst there were similarities between the current study and the Karp and Tanarugsachock (2000) study in terms of types of expressed emotion, carers in the current study differed in that they understood emotional reactions within a religious framework. For example many carers understood the emotions of anger and empathy in relation to a religious understanding of the meaning of suffering.

Participants in the current study were able to conjure positive emotions, for example hope, in the midst of managing high levels of anxiety and unpredictability. The presence of positive emotion within stressful situations has been linked with religious beliefs (Schwartz & Gidron, 2002), and may relate to resilience (Miller, 2006), religious ritual, for example use of prayer (Segall & Wykle, 1988) or to the

ability to find positive meaning during challenging life events (Coyle, 2002). Understanding the cause of psychosis was a key feature in the narratives of participants within this study. Carers often had very little psychological knowledge about psychosis, and therefore there was a drive to understand psychosis within a familiar religious knowledge framework. These findings suggest that an important aspect of religious coping for these participants was the ability to integrate understandings of the causes of stressors into an established belief framework of the self and of the world (Folkman & Moskowitz, 2004).

Understanding care-giving experiences within the context of meaningful suffering often provided a source of hope and strength which facilitated the maintenance of the caring relationship. Even participants who had been caring for many years still engaged with hope that the care recipient's mental health difficulties would improve, and that eventually they would understand more fully the reasons for their suffering. For some this was translated into concerns for the care recipient on "judgement day", and for others this was viewed as hope that in the future the care recipient would turn to God for healing. Therefore the current study suggests that patterns of illness acceptance were influenced by religious beliefs about the future. Other research suggests that positive symptom management is related to acceptance of the current situation as opposed to belief in the permanence of illness (Gaudiano, 2005). Therefore it is possible that participants contributed to the positive symptom management of the care recipients through acceptance of current symptoms, whilst also maintaining hope for future recovery.

4.4 How did Carers Make Sense of Psychosis within a Religious Frame of Reference?

4.4.1 Suffering as a Meaning Framework

Many participants conceptualised challenging care-giving experiences and the psychosis-related experiences of the care recipient, as meaningful suffering. Gottlieb and Gignac (1996) suggested that for carers of people with dementia, searching for meaning at times of adversity was the most common coping strategy. Within the current study understanding suffering as meaningful facilitated beliefs about a religious purpose to difficult caring experiences. Related to this, participants engaged in downward social comparisons, comparing themselves with carers who they perceived to be experiencing relatively meaningless non-religious suffering. These comparisons appeared to increase the psychological well-being, and this concurs with other research, suggesting downward social comparisons can improve self-esteem (Wills, 1987).

4.5 How did Mental Health Services Interact with Carers and their Religious Beliefs?

4.5.1 Negotiating Mental Health Services

Carers believed that mental health services were unable to give them reassurance about the future course of the psychosis and this generated extra reliance on religious coping systems which gave meaning to suffering. Participants often directed anger at services and it is possible that this formed an adaptive but painful stage in relinquishing future hopes for the care recipient (Karp & Tanarugsachock, 2000). However other studies have also indicated carer dissatisfaction with mental health services regarding a range of issues including feeling excluded from services and being given little information about psychosis (Knudson & Coyle, 2000). Within this

study carers were more likely to be dissatisfied with mental health services when they perceived services to be disrespectful of their religious beliefs. Furthermore, results suggest that religious beliefs were intensified in the face of service criticism. These findings have been echoed in other research which proposes that threats to religious coping systems increase adherence to fundamentalist religious beliefs and authoritarian thinking (Shaffer & Hastings, 2007).

Within the current study, when participants believed that services were disrespectful of their religious coping beliefs they often psychologically distanced service input from their understanding of God's will. For some this distancing generated increased feelings of strength to advocate for service users, for others distancing created feelings of hopelessness and anger which resulted in carers disengaging from services. In contrast when carers understood mental health services to be respectful of their religious beliefs they were more likely to believe that God was favourably influencing services and this facilitated more collaborative relationships.

Carers often reported feeling blamed and silenced by mental health services with regard to their religious beliefs. This perception resulted in many carers expressing the need for a "sanctuary" where they could speak about both their religion and their role as a carer. Similar findings have also been found in religious service user populations, with experiences of stigma within mental health services being related to having both mental health problems and religious beliefs (Lindgren & Coursey, 1995). These findings suggest that both service users and carers with religious beliefs experience limitations in accessing support within mental health services. This is of concern since lack of appropriate mental health service input has been linked to

higher levels of caregiver burden (Kuipers & Bebbington, 2005), and increased

relapse rates in service users (Fowler, Garety & Kuipers, 1995).

4.6 How did Social Support Systems Influence Coping?

4.6.1 Utilising Social Support Systems

Access to social support systems related to perceived care recipient need. Therefore if

the care recipient's mental health was particularly unpredictable participants often

believed that care recipients needed constant care and therefore social support systems

were significantly restricted. The care recipient's beliefs about the specific nature of

the social support also impacted on access, for example paranoid beliefs were often

reported to impact on attendance at carers support groups. Therefore participants

experienced difficulties in accessing support systems that would meet both carer and

care recipient needs. These results concur with research suggesting that coping

strategies, which are helpful for one partner in a caring relationship, may be

detrimental to the other (Folkman & Moskowitz, 2004). Coyne and Smith (1991)

concluded that for patients following a myocardial infarction, strategies that reduced

stress in the patient, increased stress in the carer. These findings have implications

for standardised models of care which assume homogeneity of support need in the

carer-care recipient relationship.

Participants also accessed social support which stemmed from religious

organisations. Carers had mixed experiences in terms of the perceived benefits of this

support. They experienced benefits in feeling supported by people with similar

religious beliefs, but also often felt that they could not share their caring experiences,

because of the perceived stigma associated with mental health problems. Other

research has suggested that religious service users have experienced barriers to

accessing religious social support for similar reasons (Little, 2006). These

experiences echo those that were suggested in relation to accessing support from mental health services. It seems that many participants experienced mental health-related stigma when attempting to access religious social support, and religion-related stigma when trying to access mental health related social support.

4.7 Conclusions and Clinical Implications

To sum up, participants utilised a range of religious coping strategies with selection relating to available external support systems, relationship with the care recipient and the degree to which carers believed that they were responsible for problem resolution. When carers experienced caring to be particularly unpredictable and believed they had little positive impact on the care-giving relationship they were more likely to increase their commitment to the caring role and to use coping strategies which emphasised "God control". Religious coping strategies provided an understanding of psychosis and increased hope and strength to continue caring, however these beliefs were more problematic when interacting with services or service users who attributed different meanings to the causes of psychosis.

Results suggested that carers required more information about psychosis and support at times when the care recipient's mental health was particularly unpredictable in presentation. Unfortunately both current findings and previous research suggest that at times of acute need both carers and service users can experience blame and stigma in relation to their religious beliefs (Little, 2006), which can result in carers disengaging from mental health services. This is a particularly concerning finding for several reasons. Firstly, clinicians working within the National Health Service have a statutory duty of care to support carers and respect their religious beliefs (Department of Health, 1999). Secondly, current results suggest

religious beliefs to be an important source of hope and strength for carers. Thirdly, carers are a vital source of support for service users and therefore also crucial in facilitating engagement between mental health services and service users. Carers also often provide twenty-four hour care and are therefore well placed to notice deterioration in the mental health of service users. Therefore good working relationships between carers and services is likely to contribute to preventing relapse and psychiatric admission.

Carers also provide vital information contributing to important decision-making processes, for example in Mental Health Act assessments (Churchill, Wall, Hotopf, Buchanan & Wessely, 1999). Therefore impoverished communication between carers and mental health services could jeopardise standards of care for service users. Finally, at times of acute caring need carers are particularly susceptible to physical and mental health problems (Knudson & Coyle, 2002), therefore through providing inadequate support, services risk increasing social isolation and thus facilitating adverse psychological effects in this population.

There are clearly significant clinical implications for both carers and service users when services are perceived as being disrespectful of religious beliefs. Some previous research has suggested a negative association between positive mental health and some specific religious practices (Bergin, Stinchfield, Gaskin, Masters & Sullivan, 1988), and this may have contributed to carers' beliefs about blame. However mental health services now primarily understand psychosis within a bio-psycho-social model, which could incorporate religious coping strategies as protective psychological factors, however it does not easily incorporate beliefs about potential religious causes of psychosis, for example that psychosis is part of a God given trial. When this is coupled with difficulties that clinicians have encountered in engaging with religious

beliefs in therapeutic practice (Seybold & Hill, 2001), it becomes clear that there are both theoretical and practical divides between religious understandings of psychosis and mental health service understandings.

Given the secular foundations of mental health services, bridging the divide between services and carers with religious beliefs will require proactive working relationships that engage and support carers before they reach crisis. The Carers (Recognition and Services) Act (Department of Health, 1995) entitles all carers to a social services assessment of need, and this seems a valuable opportunity for engagement with carers and their religious beliefs. Encouraging open discourse about religious beliefs would facilitate the acknowledgement and support of religious beliefs. This approach is more likely to engage carers and to provide a platform from which to build future working relationships. Current results suggest that carers struggle to manage caring with other role responsibilities, and that this is intensified when the care recipient's mental health is particularly unpredictable. Therefore carers also require timely information about psychosis and available treatment options, and a tailored approach to family interventions which account for differing needs between family members (Kuipers & Bebbington, 2005).

Within the current study carers expressed the need for a "sanctuary" where they could discuss both religious beliefs and caring. Therefore services should be more ready to engage in facilitating links with religious organisations, in particular facilitating relationships between religious carers and religious representatives both within and outside of the NHS. This is particularly pertinent at present when chaplaincy services are experiencing reductions in funding.

4.8 Methodological Critique

Having considered research findings and clinical implications, this section now focuses in more detail on pertinent methodological issues. Grounded theory emphasises the importance of the researcher remaining aware of her assumptions and biases throughout the research process. It was likely that both the researcher's religious beliefs and her experiences of working with carers of people with psychosis influenced the interview process and interpretation of results. Therefore the researcher utilised a reflexive practice diary and supervision to help manage biases and account for them in the theory development.

Other limitations stem from difficulties in strictly adhering to interview schedules and the impact that different interview venues had on the interview process. For example interviews conducted at the carers' homes may have been influenced by the need to keep some information confidential from care recipients, who were on occasion in the house at the time. In addition it is likely that the researcher's position as a trainee clinical psychologist influenced participant narratives, this was demonstrated when participants asked the researcher about her clinical opinion on personal issues.

Despite these limitations the researcher believed that the theoretical research model was richly developed, and the core category was "theoretically saturated". However, there were some categories that would have benefited from further development. For example the main category of "negotiating role responsibility", would have benefited from including more participants who were employed, as this was a key issue that emerged toward the end of the study.

Results are likely to have relevance for other "religious" carers of people with psychosis, however the relevance of these results may alter over time in relation to developments in mental health service approaches to people with religious beliefs.

4.9 Future Research

Participants within this study were predominantly Christian, therefore future research would benefit from accessing other religious populations. This could better inform services about how to engage carers and service users from religious minority groups which are currently under-represented in mental health services (Juthani, 2001). In addition current participants received NHS input, therefore in developing the findings it would be useful to interview religious carers who had not accessed NHS support. This would provide information about how religious carers cope with caring when their beliefs about the aetiology of psychosis are not opposed by services.

Finally more research is needed in examining the process of "using religion as a balancing act", particularly exploring in more detail the critical points at which carers change in their beliefs about the extent to which God is responsible for resolving challenging care-giving situations. It would also be useful to explore whether carers hold dichotomous relationships with God, for example that God is both loving and punishing, and if so how this is managed and understood. This information would help inform clinicians about how religious beliefs impact on coping behaviours.

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SECTION C: Critical Appraisal

1. Chapter Overview

This section critically appraises the research process and reflects on the research-researcher relationship and the impact of this on research findings and processes. It concentrates on the decisions, dilemmas and tensions which were faced during the research process, and relates these to both limitations and future research.

2. Design

2.1 Development of the Research Question

Prior to beginning clinical training, the researcher conducted a piece of qualitative research exploring the experiences of carers of people with severe and enduring mental health problems. In addition, in her first year of clinical training, she worked within a rehabilitation and recovery clinical psychology department for people with severe and enduring mental health problems. In this time she undertook clinical work with carers and became aware of the use of religious beliefs in supporting carers through stressful situations. Therefore the researcher had an established interest in continuing to explore carer experiences.

Working with carers of people with psychosis, the researcher became interested in how carer's religious beliefs interacted with those of the care recipient. She also knew of literature suggesting that clinical psychologists faced challenges in working with religious issues in clinical practice (Crossley & Salter, 2005), and wondered whether this was a common experience for mental health professionals, and if so how this affected carers with a faith background? These ideas contributed to development of the central research question which aimed to explore how carers used religion in coping with their carer role. Since this was an exploratory piece of research that centred on individual experiences, the researcher decided that qualitative methodologies might be most appropriate.

2.2 Choosing a Methodology

The researcher considered using several qualitative methodologies, including Interpretative Phenomenological Analysis, Discourse Analysis and Grounded Theory. She was keen to access participants from a variety of faith backgrounds and carer relationships. Therefore due to the heterogeneous nature of the proposed participant population, grounded theory was chosen as the most appropriate methodology. The researcher had not used grounded theory before and so she familiarised herself with a new methodology and with issues of related epistemology. The researcher's epistemological stance was "critical realist". The grounded theory method fits well with the critical realist position as it emphasises the importance of individual experiences and beliefs within social context, and allows for in-depth development of both similarities and differences of individual experience.

With the critical realist stance in mind the researcher familiarised herself with several versions of grounded theory (Henwood & Pidgeon, 1992; Strauss & Corbin, 1998). In retrospect each of these approaches influenced the research process. However, whilst the researcher was in the process of deliberation over choosing the most appropriate grounded theory methodology she attended a qualitative research conference where she was able to hear Kathy Charmaz present, and this influenced her decision to follow the Charmaz (2006) model of grounded theory. In addition, this model emphasises researcher reflexivity and provides helpful method frameworks to enable reflexive awareness. It also emphasises useful methods to enhance data-theory coherence, for example memo writing and theoretical sampling. Researcher reflexivity and data-theory coherence encourage researcher accountability and are central tenets within the critical realist epistemology.

3. Participants

3.1 Initial Interest

The researcher's clinical work had facilitated a working relationship with a local carers' support group manager. Therefore the researcher approached her with a view to establishing research viability in terms of carer interest and recruitment. The manager suggested that the researcher place advertisements in the carers' newsletter and present the research proposal at a support group meeting. However following this no participants opted into the research.

3.2 Carers' Group Meetings

Due to a lack of participants, the researcher contacted four other carers groups and instigated the same procedure of sending flyers in carers' newsletters and asking to present the research proposal at group meetings. All carers' groups were supportive of this, and several participants came forward. Presenting at the carers' group meetings was an interesting experience, and the researcher noted that groups differed in how much they aligned the researcher with NHS mental health provision. One presentation particularly interested the researcher because she had expected to present the research proposal for a short time at the end of a group meeting, however the group expected her to facilitate the whole meeting. In addition many of the participants did not speak English as their first language. This group was community-focused and members had brought food to share. Therefore the researcher changed her approach and spent the session talking with the carers about the background to the research. Participants shared their experiences of using religious beliefs in their coping as carers, and were keen for the researcher to audiotape the session. Unfortunately the researcher did not have ethical permission for this and therefore this was not possible. However in many senses the meeting was more akin to a focus

group than a recruitment opportunity. This also differed from previous groups because participants wanted to know more about the researcher's religious background, which was different from all the other participants. Therefore this meeting informed the development of the interview schedule and provided insight into how it felt to have personal questions asked about faith background.

4. Procedure

4.1 Data Collection

The researcher felt that it would facilitate participant recruitment if she was as flexible as possible in terms of interview venue. Therefore interviews took place in a variety of settings including health centres, carers centre facilities, participants' homes and university accommodation. The researcher was aware that different venues had potential to impact on interview process. For example interviews conducted at the carers' homes may have been influenced by the need to keep some information confidential from care recipients, who were on occasion in the house at the time. This emphasised negotiation of carer role responsibilities, which later became a main category within the theoretical model. Therefore in some instances it was both the interview process and the interview content that informed theoretical thinking.

4.2 Confidentiality Issues

Confidentiality issues were particularly apparent on one occasion when the participant's employer asked the researcher why she was meeting with the carer. The researcher was unsure how much the carer's employer knew about her, and therefore managed confidentiality issues through being vague about the research aims and mentioning this to the carer at the time of interview. Again, this process emphasised another aspect of negotiating carer and employment responsibilities.

4.3 Interview Rapport

The researcher felt that generating a positive rapport with participants would encourage a trusting interview environment and would therefore promote more open and honest accounts of experiences. Therefore interviews began by introducing the research area, mentioning issues of confidentiality, asking for consent forms to be signed and giving participants time to ask questions. This procedure also created some contextual boundaries through reminding the researcher that this was a research interview as opposed to a clinical interview. Despite this the researcher was aware that she used her clinical skills in creating a rapport and in summarising salient information and asking open-ended questions. She felt that it was important to ensure that participants had understood questions, and that she had understood responses as this reduced the likelihood of acquiescence. At times the researcher would have liked to have offered therapeutic input to carers, especially when she was eliciting distressing narratives. It was also difficult for the participants to maintain a research relationship with the researcher and they often asked the researcher about her clinical opinion on personal issues. This was managed through returning the participants to the research process, therefore, rather than answer specific clinical questions, the researcher reflected on relevant experiences that other carers had raised in interviews.

Whilst the researcher tried to maintain boundaries between research and clinical emphasis, several of the participants reported that the interview had been "therapeutic". The extent to which they found discussions therapeutic related to whether they put the researcher in the position of "witnessing" their narrative or in the "expert" position. Reflections following these interviews prompted the researcher to revisit interview transcripts, which suggested that the emphasis which participants had placed within narratives may have related in part to their motivation to attend the

interview. For instance one participant, who placed the researcher in the "expert" role, also emphasised lack of service provision.

4.4 Eliciting Distressing Narratives

On two occasions the researcher supported participants in sharing distressing experiences. In particular this related to questions regarding the cause of the care recipient's psychosis, which often stemmed from traumatic events. These questions primarily elicited narratives of participant guilt and created a challenging dynamic in terms of the researcher feeling drawn toward a clinical role rather than a research role. Participants were reassured that they did not have to discuss difficult memories and emotions, but their choice to share these narratives was also respected. The researcher also checked that participants were aware that they could speak to counsellors within the carers' centres. Whilst the researcher managed the dynamic within the interview, she was left feeling concerned that she had elicited difficult information from participants without this being the basis for clinical intervention. It was useful for the researcher to try and discuss these feelings within clinical supervision, and to remain aware of them throughout the research process.

4.5 Adherence to Interview Schedules

The researcher used theoretical sampling to inform the interview schedule, and therefore the interview schedule changed following each interview (see Appendix I). The researcher was keen to cover all aspects of the interview schedule but also to allow flexibility to facilitate exploration of new areas of interest (Charmaz, 2006). Several challenges were experienced in adherence to the interview schedule. For example, before the first interview one respondent asked the researcher to read a diary that she had written about her experiences of caring for her son. The researcher felt

that it might affect interview rapport if she refused to read it although she was aware that this would influence the questions asked in the interview. Therefore she read the diary, however this created difficulties within the interview as the participant repeatedly reminded the researcher that details she was asking about were in the diary. The researcher then experienced a tension through on one hand not wanting the participant to repeat information but on the other, wanting experiences to be included within the data. Strict adherence to grounded theory method would suggest that the researcher should not have read the diary because of potential research bias, however the researcher managed this through reflecting on this process and remaining aware of her assumptions within the interview and analysis (Charmaz, 2006).

Other interviews created difficulties in adhering to the interview schedule due to competing dominant narratives and narrative structures. For example one interviewee insisted on giving a chronological account of her caring experiences, which spanned twenty years. The researcher tried to directly focus the interview, however eventually she felt that it would be detrimental to the rapport to insist on imposing her structure on the interview. Therefore she opted to try and explore issues that corresponded with the interview schedule when they were mentioned in the interview. Another carer was very angry with mental health service provision and wanted to focus on telling the researcher her grievances. The researcher decided that it would be better to let her talk about these frustrations and then later to try and focus the interview. Whilst the researcher acknowledges that these differences may have impacted on theoretical sampling procedures she felt that the interview schedule topics were generally covered.

4.6 Researcher Bias

Criticism of grounded theory has often related to concerns that the analysis may simply reflect the researcher's interests and biases (Schwandt, 1994). Therefore ideally grounded theory should be conducted without initial hypotheses or preconceptions, so that analysis is inductive and participants are able to guide the interview process (Coyne, 1997). However the researcher was working with carers and service users in clinical psychology psychosis services and therefore she was aware of many relevant issues before beginning the research process. The researcher reflected on these limitations in supervision and used the constant comparative method to help her remain aware of her biases and try and account for them in the theory development. Additionally, the researcher was required to complete her literature review in her first year of clinical training and therefore she was aware of relevant literature before starting the interview process. This reflection influenced her choice to engage with writing a revised literature review after the interviews had been completed, and this helped the analysis to remain grounded in the data (Rennie, 2000). The analytic process also influenced the key literature that was attended to within the literature review, and this created a more connected piece of work that centred more on participant experience than researcher preconceptions.

4.7 Issues of Conversion

One participant highlighted the difference between her faith beliefs and the researcher's. The researcher felt that this was difficult for the participant and therefore she emphasised that she would listen to the participant's experiences in a non-judgmental way but also that the participant could opt out of the research process at any time. After the interview had been conducted, the researcher found that she had been sent information about the participant's Seventh Day Adventist Church in

the post. The researcher felt that having a different religious belief system from the interviewee had created a threat to engagement and rapport. This raised issues for the researcher in terms of standpoint epistemology. It could be argued that in line with feminist standpoint research (Stanley & Wise, 2000), different experiences between interviewer and interviewee create barriers to engagement, however others have argued that differing perspectives allow for greater focus upon detail which may go unnoticed by those that share similar experiences or backgrounds (Heaphey, Weeks & Donovan, 1998). It would be interesting for future research to explore the influence of similar religious standpoints on interview rapport and narrative emphasis.

5. Data Analysis

5.1 Transcribing

The researcher personally transcribed each interview before conducting the next, and she believed that this helped her to remain grounded and connected with the data. During the transcription process the researcher was often reminded of issues which she included in the reflexive practice diary. Transcription also aided clarity and informed early memos, which usually related to questions about future expansions of the interview schedule. These memos were also used as a reminder at the coding stage.

5.2 Initial Coding

The initial coding of each transcript was also conducted before continuing the interview process. Initial coding allowed specific focus on words or lines of data that conveyed key ideas or actions (Appendix J). Tentative labels were attached to "chunks" of data, and were often revised at later analytic stages. Codes allowed the researcher to compare incidents within interviews and between interviews. The

researcher often found it challenging not to impose her own immediate rationalisation onto the data and to wait to uncover meanings. At times the researcher established competing codes for the same section of data, for example literal translation and projected participant meaning. Choices about most appropriate codes were made through critical reflection in supervision. Challenges in analysis were also documented and used at later analytic stages to compare with focused and theoretical coding. The researcher also collaborated with peers in her qualitative support group and was reassured that the initial coding was extremely similar to others' interpretations.

5.3 Focused Coding

Focused coding was more conceptual and directive than initial coding (see Appendix K). Analytic codes were assigned to data sections. This facilitated the development of hierarchical analytic categories, which were compared within and between transcripts. Distinctions were made between categories that reflected process and those, which reflected specific content. Generally, focused coding was also completed after each interview and these focused codes provided a structure from which to expand and refine the interview schedule. The researcher tried to stay as open as possible to emerging themes; at times this was challenging since it was tempting to apply previously constructed categorisations to new data.

5.4 Theoretical Coding

Theoretical coding allowed a better understanding of both the universal and the discrepant processes emerging within the data. The researcher found it challenging to reformulate theory, which had previously been fractured from the data (Charmaz, 2006). She consistently found she developed codes that were not "theoretical"

enough and were more descriptive, this then developed into a model that resembled more of a care pathway than a theoretical process model. The researcher used supervision to help group lower categories into more abstract ideas. However the core category "using religion as a balancing act" was not developed until interview nine, when a participant spoke directly about using religious beliefs to balance different areas of her life. This allowed the researcher to adapt her interview schedule to ask about this category in interview ten, and also use the constant comparison method to revisit data and coding to check for adherence.

5.5 Memo Writing

"Early" memo writing was found to assist grounding of theory in the data (Charmaz, 2006) and in generating new theory (Charmaz, 2003). Memos contained thoughts about how categories related within and between each other and expanded on new concepts. They also allowed a more liberal reflection of the researcher's ideas which could include ideas from out with the immediate transcript, for example thoughts stemming from literature, personal experience or clinical practice. Memos were generally included within the reflexive practice diary. Emphasis within memos changed throughout the research process. At the beginning memos were less structured and generally related to future interview schedule questions. They also included ideas about the theory or the process which particularly puzzled or intrigued the researcher and these were often used to ground discussion in supervision (see Appendix L).

An example of memo-generated change stemmed from questions within the initial interview schedules regarding use of either religious or spiritual beliefs in coping with the carer role. Through memo writing it became apparent that participants did not relate to the concept of spirituality as a discrete entity, but rather saw it as a part of

their religious beliefs. The researcher deliberated about whether to use theoretical sampling to recruit participants who related to a defined concept of spirituality or whether to focus the interview schedule on religious beliefs. She decided that she would focus on religion rather than spirituality because of the ambiguous nature of conceptualising "spirituality" (Pargament, 1997) and time constraints. However it would be interesting for future research to explore in more detail the relationship between religion and spirituality, especially since the concept of modern "spirituality" is often grounded in Western culture. One participant spoke of not acknowledging spirituality as a concept, and it would be interesting to see how people from different cultural and religious backgrounds understand the concept of spirituality. In contrast, toward the end of the process, "advanced" memos helped ground the researcher in the data whilst she also became increasingly focussed on theoretical more abstract categorisations.

6. Methods Used to Enhance the Quality of Research
6.1 Constant Comparative Method

The researcher worked interchangeably between coding processes. Codes were revised and completed simultaneously. Similarly, whilst theoretical coding was more prevalent toward the end of the analytic process, the researcher continually crosschecked the emerging concepts with the data, initial coding and theoretical coding. The researcher found that different stages of the research lent themselves better to the constant comparison method. For example, at the beginning of the research the constant comparative method was useful in facilitating the development of revised interview schedules.

Toward the end of the analysis when the researcher was engaged in theoretical coding, she felt that the richness of the data had been "lost" in higher theoretical

categories. Therefore the researcher returned to the initial interview coding and worked backwards from theoretical categories to ensure that the raw data fitted with the theoretical model. This was a valuable process as it renewed the grounding of the researcher in the data; however the researcher also found that anxieties regarding not "misrepresenting" the raw data were generated.

The researcher thought it to be important to disseminate research findings and raise awareness of religious coping in the carer population. Therefore participants received copies of the interview transcripts and were invited to contact the researcher with any queries. One participant contacted the researcher regarding spelling errors. Furthermore, the researcher plans to disseminate a research summary to each of the participants and publish findings in appropriate carers newsletters.

6.2 Credibility Checks

The researcher regularly attended a qualitative support group including seven peers and a supervisor who was familiar with grounded theory methodology. This allowed inter-rater validation with regard to analysis of a selection of transcripts. The group also acted as a source of information when identifying researcher bias, for example it was identified in the group that the researcher felt "protective" of the participant narratives. This allowed her to realise that this stemmed from clinical practice when she was often required to advocate for carers, rather than critically evaluate their narratives. This insight allowed the researcher to revisit the data and be more analytic in her approach.

The researcher also presented her theoretical process model at a conference entitled "Why Would Anyone Believe in God?" organised by the British Association of Christians in Psychology. This was particularly helpful, since the researcher presented in conjunction with two other researchers. Their interest in exploring

religious practice of people with psychosis, and in how clinical psychologists negotiated religious beliefs in clinical practice helped the researcher contextualise her own research. It was also encouraging for the researcher to receive endorsement of the credibility of the research model from conference delegates and peers.

6.3 Detailed Procedure

The researcher ensured that there was a clear research process. This was important so that she was clear about procedure, particularly given the time constraints of the project. The researcher was aware that there were other issues that developed from the interviews that she would have like to pursue in the future; however they had little relevance to the research question and therefore they were not developed. An example of this was how carers described the impact that the ward environment had on care recipients or the process of diagnosis.

6.4 Theoretical Sampling

Initially theoretical sampling was directed at altering the interview schedule to expand and develop emerging categories. It was less necessary to use theoretical sampling to recruit particular participants as participants from a variety of cultural and religious backgrounds and with different familial relationships to the care recipient opted into the research. However it was apparent that all the participants that had opted in were women and the researcher was interested in a male caring perspective. Therefore the researcher asked a local carers manager if she could recommend a male carer and if he was interested, give them the information. This carer did opt into the research, however at interview it also became apparent that he had also been a service user and this added an unforeseen dimension to the theoretical sampling. Following this interview the researcher reflected that she had felt a tension in wanting to access carer

experiences, but not wanting to over-emphasise the concept of "carer burden", because of the potential psychological impact on the participant in terms of his previous role as a care recipient. This insight highlighted that at times the researcher viewed the caring experience in predominantly negative terms, and prompted a return to the data with a more open stance toward positive caring experiences.

7. Research Limitations and Future Research

The current study relied heavily on the use of both retrospective reports and introspection. On occasion participants reported that they found it difficult to remember relevant events, especially as they may have occurred several years previously. One carer said that she used to write events down in a diary, but that this became too distressing and therefore she stopped. Therefore narratives may have been influenced by problems in remembering relevant incidents and also the emotional impact of recollecting narratives. Future research might reduce the impact of these limitations through pairing interviews with use of a diary. This would allow participants to use a memory aid and would also encourage contemporaneous recollections. Related to this, a longitudinal study would allow access to a more detailed change process over time. In this way it would exemplify in more detail the core category "using religion as a balancing act", as the change in participant coping strategies would be more explicit.

The current study recruited participants from carers' support groups stemming from the NHS and the voluntary sector. Participants were aware that the researcher was employed by the NHS, and were informed that participating in the research would have no influence on service provision for care recipients. However some of the anxiety and worry that was raised at interviews may have related to concerns about potentially affecting treatment options. In contrast participants may have

viewed the researcher as a "representative" of the NHS, and in this sense they may have over-emphasised aspects of care about which they were unhappy with the hope that changes to service provision might be made. A researcher who was independent of the NHS may have limited some of the participant bias in this regard. However, it is possible that this would have also created barriers in terms of less familiarity with NHS systems.

Due to time constraints only ten participants were interviewed. Whilst the researcher felt that toward the end of the interviews categories were becoming "saturated" and few new categories were emerging, there were categories that would have benefited from development. For example the main category "utilising support systems" was mentioned in all interviews; however the research could have explored in more detail the choice processes in accessing support. Therefore the researcher felt that the study would have benefited from interviewing more participants, and within this including more male participants and participants from other faith backgrounds. All participants had contact with NHS mental health systems and this was represented within the theoretical model in terms of negotiating these systems. The impact that the mental health system had on all participants was significant. Therefore interviewing carers who had not accessed services would add another dimension to the current study. Therefore more research is needed to explore how access to services can be improved for minority religious groups, and in contrast how carers manage without mental health service support.

8. Clinical Implications

Henwood and Pidgeon (1992) suggested that the researcher should not remain unaffected by the research procedure. The researcher felt that she had integrated much of what she had learned from the interview process into her clinical work. This

was particularly relevant when working with carers and service users with religious beliefs, and generated discussion in supervision about the ways in which other clinicians work with religious issues in their practice. The research process also made her think in more detail about her religious belief standpoint in relation to her clients; for example, under what circumstances it might be appropriate to share similar or differing religious beliefs within clinical practice?

The research was also useful in providing impetus for two participants to request religious speakers at the carers' support groups, and to open up discussion about the use of religious beliefs as sources of support for carers. In this sense the research had direct impact in alleviating some of the stigma attached to the discussion of religious beliefs. This group was facilitated by NHS staff and therefore this also raised staff awareness of religious and spiritual issues in working with carers and service users. The researcher plans to revisit each of the participant groups and disseminate research findings. It is hoped that in a similar way this might also raise awareness of religious carer experiences.

Other clinical implications include the need to consider carer religious belief systems within clinical practice. This is necessary in terms of clinicians showing an open curiosity and respect for these beliefs but also in not criticising religious methods of coping. The current theoretical model suggests that not accepting religious beliefs is likely to alienate carers from mental health services, reduce available support and align carers more strongly with religious beliefs. Furthermore the results suggest that carers require clear and individually tailored information that is appropriate to their journey in relation to the illness progression. Information is particularly necessary in terms of reducing the impact of the unpredictability of caring

for someone with psychosis. This may be achieved through equipping carers with a range of coping strategies that can be adapted to both acute and chronic situations.

9. Conclusions

The process of conducting the research and using grounded theory to explore the experiences of carers was both challenging and rewarding. The researcher did not intend that the theoretical model generated should be "generalisable" to all carers; rather the intention was to provide a greater depth of insight into these issues. The researcher aimed for a theoretical model which had explanatory power (Strauss & Corbin, 1998), and that could be adapted to generate interest in carer experiences both for carers of people with psychosis and different carer populations (Erlandson, Harris & Skipper, 1993). Many of the psychological processes present within the model may be relevant to other clinical populations. For example "negotiating unpredictability", is likely to relate to other clinical conditions that fluctuate in clinical presentation, such as cancer patients.

The research process highlighted the "dilemma of the qualitative method" (Henwood & Pidgeon, 2002). The researcher was aware of the tension between trying to stand objectively outside of the research process to enable perspective, whilst also being a part of the research and being aware that her own experiences and biases impacted on the final theoretical model. However the researcher hoped that through being as "transparent" as possible and also keeping an "audit trail" of decisions and dilemmas, the research process was made both accountable and accessible.

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SECTION D: Appendices

Appendix A: Publishing Guidelines for the British Journal of Clinical Psychology

The British Journal of Clinical Psychology publishes original contributions to scientific knowledge in clinical psychology. This includes descriptive comparisons, as well as studies of the assessment, aetiology and treatment of people with a wide range of psychological problems in all age groups and settings. The level of analysis of studies ranges from biological influences on individual behaviour through to studies of psychological interventions and treatments on individuals, dyads, families and groups, to investigations of the relationships between explicitly social and psychological levels of analysis.

The following types of paper are invited:
- Papers reporting original empirical investigations;
- Theoretical papers, provided that these are sufficiently related to the empirical data;
- Review articles which need not be exhaustive but which should give an interpretation of the state of the research in a given field and, where appropriate, identify its clinical implications;
- Brief reports and comments.

Manuscript requirements
- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.
- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate page. The resolution of digital images must be at least 300 dpi.
- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions: British Journal of Clinical Psychology - Structured Abstracts Information
- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full.
- SI units must be used for all measurements, rounded off to practical values if appropriate, with the Imperial equivalent in parentheses.
- In normal circumstances, effect size should be incorporated.
- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations etc for which they do not own copyright.

For Guidelines on editorial style, please consult the *APA Publication Manual* published by the American Psychological Association, Washington DC,USA (http://www.apastyle.org).

Appendix B: Ethical Confirmation

NHS

Leicestershire, Northamptonshire & Rutland Research Ethics Committee 2

Research Ethics Office
Derwent Shared Services
Laurie House
Colyear Street
DERBY
DE1 1LJ
Telephone: 01332 868842
22 February 2006

Miss Sarah Longbotham
Trainee Clinical Psychologist
Leicestershire Partnership NHS Trust
School of Clinical Psychology
University of Leicester, 104 Regent Road
Leicester
LE1 7LT

Dear Miss Longbotham

Full title of study:	**An Exploration of the use of Spirituality/ Religion as a Coping Strategy in lives of people with Psychosis**
REC reference number:	**06/Q2502/14**

Thank you for your letter of 08 March 2006, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion
On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites
The Committee has not yet been notified of the outcome of any site-specific assessment (SSA) for the research site(s) taking part in this study. The favourable opinion does not therefore apply to any site at present. I will write to you again as soon as one Local Research Ethics Committee has notified the outcome of a SSA. In the meantime no study procedures should be instigated at sites requiring SSA.

Conditions of approval
The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents
The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Application	V1 13.01.2006	13 January 2006
Investigator CV	Designated Version 1	

Protocol	Version 2	08 March 2006
Interview Schedules/Topic Guides	V2 Appendix A	08 March 2006
Letter of invitation to participant	V2 Appendix B	08 March 2006
Participant Information Sheet	V2 Appendix C	08 March 2006
Response to Request for Further Information	08th March 2006	08 March 2006
Other	Flow Chart V2 Appendix E	08 March 2006
Other	Details of Advert V2 Appendix F	08 March 2006
Other	Supervisor CV (designated Version 1)	

Research governance approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final research governance approval from the R & D Department for the relevant NHS care organisation.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

06/Q2502/14	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project
Yours sincerely

Chair

Email: sarah.gill@derwentsharedservices.nhs.uk

Enclosures:	*Standard approval conditions (SL-AC2)* *Site approval form*
Copy to:	Leicestershire Partnership NHS Trust, George Hine House, Gipsy Lane, Leicester.

Nottinghamshire Healthcare **NHS**

NHS Trust

E-mail: shirley.mitchell@nottshc.nhs.uk

Research & Development
Duncan Macmillan House
Porchester Road
Mapperley
Nottingham
NG3 6AA

Tel: 0115 969 1300
Fax: 0115 993 4549

Our Ref: AMH/06/04/06

06 April 2006

Miss Sarah Longbotham
Trainee Clinical Psychologist
Leicestershire Partnership NHS Trust
Clinical Psychology Department
104 Regent Road
Leicester
LE1 7LT

Dear Miss Longbotham

An exploration of the use of spirituality/religion as a coping strategy in the livs of people diagnosed with psychosis

I am writing to confirm that the above study is authorised to take place within our Trust.

This is a very interesting and important field of study. The Trust R&D Department follows up such work to assess its impact and influence on practice and policy. All research registered with the R&D Department is automatically included in the National Research Register (www.update-software.com/national/) and information on all projects is updated quarterly. Therefore, I have enclosed the National Research Register Information Sheet for you completion.

Yours sincerely

Shirley Mitchell
Research Governance Lead & Business Manager

Appendix D: University of Leicester Research Ethics Confirmation

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Dear Sarah

Your project (An exploration of how carers of someone with psychosis use religion as a coping strategy) has been approved by the Psychology Research Ethics Committee.

This e-mail is the official document of ethical approval and should be printed out and kept for your records or attached to the research report if required - this includes all undergraduate and postgraduate research.

We wish you every success with your study.

Andrew M. Colman
Psychology Research Ethics Committee Chair

Appendix E: Inclusion Criteria

Participants must have fulfilled the following requirements in order to be interviewed:

- Be a member of a carers support organisation.

- Be a primary carer for someone with a diagnosis of psychosis.

- Have had a primary caring role for at least six months.

- Utilise religion/ spirituality in their caring role.

- Be able to understand the consent requirements

- Have consented to be interviewed and audio taped.

Leicestershire Partnership NHS

NHS Trust

Invitation for carers of people with psychosis to attend an interview to discuss

their experiences with reference to their spiritual/ religious beliefs.

You are invited to take part in a piece of research, which is funded by both the University of Leicester and Leicestershire Partnership NHS Trust and is in affiliation with Carers Support Groups in Leicester and Nottingham. This study seeks to explore the experiences of carers of people who have a diagnosis of psychosis and who also have spiritual/ religious beliefs. Participants from all faith backgrounds are welcome to participate. This research area is currently under represented in the literature, and it is hoped that this study will help to raise awareness of carer issues.

Please take time to read the information sheet carefully, it is important that you understand what the research involves. Please feel free to talk to others about the research if you wish. If you are willing to be interviewed about your experiences of being a carer, please return the reply slip and you will be contacted as soon as possible.

The interview process will last between one and two hours and anonymity will be maintained throughout the research process. You are free to withdraw from the study at any time, without any services you receive being affected.

If you require any further information, or would have any queries please contact me by leaving a message with the university secretary on 0116 223 1639 or call 07787871582. You may also contact me by email: SRL13@le.ac.uk

....*Please detach here*

Name:...

I am affiliated with .... (please indicate voluntary carers association)

I am interested in being interviewed about my experiences of being a carer of someone with a diagnosis of psychosis. I am aware that this research will explore these experiences with reference to my religious/ spiritual belief systems.

Please contact me by phone...................................or by letter at:

....

....

Return to Sarah Longbotham, School of Clinical Psychology, University of Leicester, 104 Regent Road, Leicester, LE1 7LT. Email: SRL13@le.ac.uk

Leicestershire Partnership NHS

NHS Trust

Research looking at the experiences of carers of someone with psychosis and their use of spirituality/ religion with regard this role.

<u>What is the purpose of the study?</u>

There is very little research that focuses on the needs and experiences of carers of people with psychosis. Specifically there is no current research that relates these experiences to the spiritual/ religious background of the carer and how this relates to the caring role. There is evidence to suggest that carers are dissatisfied with mental health services, both in relation to carer's own needs and of those of the people they care for. Therefore, this research hopes to highlight some of these issues, with a view to informing and bettering clinical practice and understanding.

<u>What will happen if I choose to take part?</u>

If you choose to participate in this research it will involve a single interview that will last between one and two hours. The interviews will be audio recorded and transcribed. Interviews will be conducted at the Carers Centre base.

It is anticipated that some of the themes that will be addressed in the interview will include:

- What it is like to be the primary carer of someone with a diagnosis of psychosis?
- How spiritual/ religious beliefs inform the caring process?
- How spiritual/ religious beliefs have been received by mental health professionals?
- How services could be improved to better provide for the needs of carers and the people they care for?

<u>Why have I been chosen?</u>

You have been chosen, because it is possible that you meet the following criteria:

- Participants are member of a carers support organisation.
- Participants are a primary carer for someone with a diagnosis of psychosis.
- Participants have had a primary caring role for at least six months.
- Participants relate to and in some way use the concepts of spirituality/ religion in their caring role.
- Participants understand and are willing to comply with the conditions of the study. You must also be willing to provide informed consent to this effect.

Do I have to take part?

No, it's up to you whether you choose to take part. If you do, you will be given this information sheet to keep and will be asked to sign a consent form. You are still free to withdraw at any time, without giving a reason. A decision to withdraw at any time, will not affect the standard of services you receive.

Are there any risks involved with taking part?

The interview will raise issues about personal religious/ spiritual beliefs in relation to the caring role. Exploring these issues may be difficult; therefore it is important that you have access to support systems, for example through your carers support organisation. Some support group numbers that might be helpful are:

- Carers Federation, Nottingham – 0115 9858485
- Leicestershire Action for Mental Health Project – 0116 2556286
- CLASP (The Carers Centre) – 0116 2510999

Will my taking part in the study be kept confidential?

Yes, the researcher will make every effort to maintain confidentiality at all stages of the research process. The only exceptions to this stem from concerns for the well-being of either carers, or people being cared for. If it is identified within the interviews, that there is a shortfall in an NHS Care Plan relating to the person you are caring for, this could be discussed with your Carers Group Manager. Similarly if the interviewer was concerned for the safety of a carer, this would be discussed with the carer and the interviewer's supervisor, who is a qualified clinical psychologist.

Whilst the interviews will be transcribed, the transcripts will be anonymised, all identifiable information relating to either yourselves or the people you care for will be erased from the transcripts. Audiotapes will be stored securely, and tapes and transcripts will be destroyed upon completion of the project. If you would like a copy of the transcript, this will be available upon request. Personalised information provided in the interviews will only be viewed by the researcher, *no* personalised information will be made available to the carers organisation.

What will happen to the results from the study?

These anonymised results will also be published as part of a doctoral thesis in clinical psychology. It is also hoped that anonymised results will be published in peer reviewed academic journals. A summary of the anonymised results of the study will also be available in your Carers News Letter. If you would like a copy of your interview, then this will be available.

If you require further information, please contact me at the following address:

Sarah Longbotham
School of Clinical Psychology
University of Leicester
104 Regent Road   Phone: 0116 223 1639
Leicester
LE1 7LT.   Email: SRL13@le.c.uk

Appendix H: Participant Consent Form

Leicestershire Partnership NHS
NHS Trust

Research exploring the experiences of carers of someone with psychosis and their use of spirituality/ religion with regard this role.

Please initial box

- I have read and understood the information and consent sheets.

- The researcher has explained the research process and aims to me, and I have had the opportunity to ask questions.

- I understand that my involvement in the research will consist of a single interview, which will be audio taped.

- I understand that I may withdraw from the study at any time without affecting any of the services I access.

- I understand that the transcripts of my interview will be stored securely, and will be destroyed upon completion of the study.

- I understand that upon request I can have a copy of the transcript of my interview

- I agree to participate in this study, as described in the information sheet.

- I agree for the interview to be audio-taped and transcribed.

- I understand that the interview will ask about my spiritual/ religious beliefs, and if talking about this should raise any sensitive issues then I have access to formal support if required.

Participant Name (BLOCK CAPITALS)..

Participant Signature..Date.........

Chief Investigator Name..

Signature..Date.........

When completed: 1 for participant, 1 for researcher site file.

Appendix I: Interview Schedule and Additions Made Due to Theoretical Sampling

Initial Interview Schedule:

<u>Introduction</u>

- Introductions

- Background to research and interview structure.

- Review of Consent and Confidentiality and Signing of Consent Forms.

<u>Caring and Religious Background</u>

- What is your relationship with the person you care for?

- What does caring involve?

- How long have you been a carer?

- What is your religious faith background?

- Why is your religious faith important to you?

<u>Experiences of Mental Health Services</u>

- How have you experienced working with mental health professionals?

- What is your understanding of the cause of psychosis and how are these the same or different from mental health professionals?

- How have mental health professionals responded to your religious beliefs?

<u>Understandings of Psychosis</u>

- Does the experience of caring change in relation to the mental health of the person you care for? If so, how do you cope with this?

- What do you understand as the cause of psychosis?

<u>Support Systems</u>

- How are you supported in your caring role?

- How do your religious beliefs help you cope with caring?

- Do religious texts influence your faith, and if so how?

- What are your experiences of accessing religious social support systems?

Ending

- Are there any questions which I have not asked which you feel would be important?

- Review Consent.

- Provide information about support systems, for if interviews have raised any difficult issues.

- Review whether they would like a copy of the transcript and a summary of research findings.

Questions added in later interviews as a result of theoretical sampling:

Interview 2

- Do you feel that the difficulties that you have encountered whilst being a carer are part of a trial?

- Do you believe that there is a cure for psychosis?

Interview 3

- Before becoming a carer how much did you know about mental health?

- Are your religious beliefs the same or different from the person that you care for, and how has this impacted on your caring relationship?

Interview 4

- Have you ever doubted your religious beliefs?

- Would you make any recommendations to help mental health services meet the needs of religious carers?

Interview 5

- How much of what you do is influenced by God's support and how much is personal control?

Interview 6

- Are there times when you rely more on your religious beliefs to support you?

- How do you envisage the future of your relationship with the person you care for?

Interview 7

- Have your family been supportive of your religious beliefs?

- How do you understand other faith positions?

Interview 8

- If you have doubts about your ability to cope, where do they come from?

- Are there times when it is harder to feel a personal connection with God?

Interview 9

- In terms of your religious belief framework how do you make sense of the difficulties that you have encountered in your caring role?

- How do you know when God has answered your prayers?

Interview 10

- How have your religious beliefs helped you to manage the unpredictability of psychosis?

- How have your religious beliefs helped you manage different role responsibilities?

Appendix J: Initial Coding Example from Interview 8.

Researcher: So why is faith important to you?

Participant: What can I say [..] because it says in the

scriptures to um./ Oh no my mind has gone blank again Sarah.

Researcher: Is your religion more about social support or is it

more an individual relationship that you have with God?

Participant: It's both,/ well social support I do get that

from one particular person/ who I was again involved in the

Christian fellowship, I see her now and again um/ and I do

like I say, I do really need to get more involved, more back

into church as a building./ Because to me church is not the

building it's the people that make up the church,/ but yes I

do need to be back with people with you know the same

faith and the same beliefs to build, you build each other up

and I feel that I want to be at home again,/ that there are

lots of people that I can turn to. Because at the moment

there is only like one or two people/ that, now that you

know the thing all split up,/ I feel that there is not enough

people within the church that I am in regular contact with./

Comment: Faith related to religious text.

Comment: Relationship with God and social support is important .

Comment: Specific important social relationship.

Comment: Less social contact than she would like? Emphasis on relationships rather than ritual.

Comment: Having the same beliefs is important.

Comment: Increased social relationships = strength.

Comment: Loss of previous relationships.

Comment: Need for more religious social support.

Researcher: So why is faith important to you?

Participant: What can I say [..] because it says in the

scriptures to um. Oh no my mind has gone blank again Sarah.

Researcher: Is your religion more about social support or is it

more an individual relationship that you have with God.

Participant: It's both, well social support I do get that

from one particular person who I was again involved in the

Christian fellowship,/ I see her now and again um and I do

like I say, I do really need to get more involved, more back

into church as a building. Because to me church is not the

building it's the people that make up the church,/ but yes I

do need to be back with people with you know the same

faith and the same beliefs to build, you build each other up

and I feel that I want to be at home again, that there are lots

of people that I can turn to./ Because at the moment there

is only like one or two people that, now that you know the

thing all split up, I feel that there is not enough people

within the church that I am in regular contact with./

> **Comment:** Recognition of religious resources.

> **Comment:** Hierarchy of resource importance.

> **Comment:** Safety in religious social support.

> **Comment:** Loss of religious relationships.

Appendix L: Example of Memo from Interview 8.

This participant talked about changes in the power relationships between her and God. At times when it was more difficult to care for her son and felt less supported by mental health services she attributed more responsibility for control to God. In contrast at other times, when she was clear about what to do in relation to her caring role, she relied on guidance from God less. Is reliance on guidance from God a last resort, which is only necessary when other coping resources are exhausted? How have previous participants fluctuated in responsibility for change? Her religious beliefs were central to gaining control over unpredictable situations. This emphasises the impact of change over time both in her relationship with God and in her relationship with her son. It also suggests a coping process, rather than static coping styles.

Appendix M: Supporting Quotes

Supporting Quotes Corresponding with Core Category – Using Religion as a

Balancing Act.

Core Category	Reference	Supporting Quote
Using Religion as a Balancing Act	P4/441	*"No idea, no idea besides what one sees in films, and that's the problem that's why people have no understanding of mental health at all."*
	P4/211	*"But because it wasn't happening to me, it was happening to my son, and such a terrible change and how it would effect not just a few months, but perhaps his whole life you just don't know how things are going to go. It was just so difficult to come to terms with it."*
	P6/295	*"My friends they don't have a very good understanding of what mental illness is, so to scare them I would rather not."*
	P3/224	*"Maybe you could turn to God and that would help you? That's what he said to her, well we went away and we talked about it, and we thought about oh turn to God. I said I'm that desperate I would turn anywhere!"*
	P4/220	*"For a while I didn't (pray), and then slowly I started again because that's the way I have been brought up always and that's the way I cope with life*

		and if I don't do that what is there left? That's the way I can manage".
	P8/246	*"I don't think doubts come from God ... I don't think he, God doesn't put doubts and there is no other entity in my opinion there is only God or Satan"*
	P2/136	*"Cos in bible time you have mentally ill, people that were possessed with daemons, we have two forces in the world today, Satan the controversy of good and evil. And Satan is in our day is taking over people's minds, I believe that, I can see that everywhere. Satan is taking over people's minds that they can't think rationally."*
	P1/15	*"From what I have heard, from what other people have said, I'm generalising really, but I think that these people* (employers) *don't want carers."*
	P5/572	*"He wanted me to go to New York with him and he wants to show me Rome in the Autumn, so provided he keeps on his tablets and he keeps well that will be OK, that will be fine."*
	P4/218	*"I could have talked to them* (family) *about it but I didn't, I haven't said anything to them at all. It was terrible, it was very difficult."*
	P7/17	*"Then she* (mother) *made a choice that OK I can look after her".*
	P8/259	*"Nobody knows enough about the illness yet to know*

		whether he is going to always suffer from it. "
	P8/51	*"Without faith I wouldn't have any hope."*
	P3/632	*"(daughter) would not tell anyone that she had been sexually abused and did not want anyone in the church to know."*
	P4/239	*"Yes, you feel the strength of God. You say well I offer it up to you as a sacrifice, but at the same time you have got to help me, you have got to help me and like that if you have a difficult time, you can cope through the day because every half an hour you pray, and every half an hour you focus."*
	P5/274	*"God doesn't intend that any of us will suffer like that, Gods intention is wholeness and healing, but men have free will, men have limited understanding, men have limited intelligence, men have limited care and love, and one hopes that most of them do their best as parents do but we are all fallible we all have weaknesses and that's how people suffer in this world, through mans fallibility, mans sinfulness, mans selfishness, mans lack of care, lack of love, lack of knowledge, because none of us are perfect."*
	P10/35	*"God as a co-creator I suppose. God is offering us the opportunity to be anything we want to be and to have total freedom over that and to create our destiny however we want to and there are examples*

		of people like Jesus who have come to earth in order to guide us towards what I see as our natural potential."
	P7/43	*"I have to talk to the GPs and the social services. So I contact the CPN, the CPN came to see me and she say you have more stress and depression than your mother."*

Category/ Subcategory	Reference	Supporting Quote
Experiencing Unpredictability	P8/117	*"I told him your eyes go really dark, it's not you, its not you it's the illness that is making you do all these things and you can't deny it because I have seen it."*
Witnessing Change.	P4/179	*"When he spoke to his friends he was a different person altogether, they come to life."*
Waiting.	P6/246	*"But you are always kind of like on edge, there is a corner in you where you question things, and also like you wait and oh what does this little change mean?"*
	P2/262	*"One of the things that I am fearful about, when he is wandering, sleeping rough, somebody might kick him to death or do something."*
Hopes for the Future.	P8/51	*"Without faith I wouldn't have any hope."*
	P9/58	*"I almost feel guilty at the moment for having this free time for not going too much near a hospital when you think that you have been averaging fifty appointments a year, then I have been just going once every couple of months now with* (husband), *um that's going to be*

	P8/261	*quite a bit of change."* *"Obviously that's my hope that he will never end up in hospital again and he will always, he will always stay well."*
Search for Guidance	P8/289	*"What I can say is that I am prepared now, I feel that God has prepared us for what could happen again, it's all up to him though."*

Category/ Subcategory	Reference	Supporting Quotes
Support Groups	P5/452	"I don't want to go to a group just to hear stressed out carers every time we go."
	P3/308	"I'm in contact with SANE now and I said I've just rung up the hospital to enquire about my daughter and they say that she is in seclusion, she wants a cigarette and a drink and she has been there two hours but they are not giving her one, I said I am very concerned, what shall I do?"
	P8/745	"They didn't give a straight answer to any of the questions, most of the time I came out really frustrated."
Religious Institutions	P3/288	"When (daughter) gave her life to Jesus, in the office, she just sat there and for the first time in goodness knows how long "I don't want a drink", and from that day on she never got into an alcoholic state again."
	P3/906	"They would take her shopping and things like that, which they had done in the other church."
Individual Information Seeking	P1/209	"When he first got ill I used the computer, but I couldn't accept that there wasn't a cure, I was very naïve, because I didn't realise that I could actually communicate with the

		rest of the world, looking for cures and reading up, that's where I learned about schizophrenia."

Supporting Quotes Corresponding with Main Category – Negotiating Role

Responsibility.

Category/ Subcategory	Reference	Supporting Quote
Negotiating Role Responsibility.	P9/206	*"The relationship changed, I think it's more that your parents become your children."*
	P3/1006	*"My husband said it must be such an awful wrench from having a girl with so much dependency on you that it must feel terrible. I said well actually it just feels a relief."*
Family Role Responsibility	P9/34	*"I got a lot of pressure to give up the ghost on* (husband) *you know they didn't believe that what he was doing was out of his control and my two sons wanted me to divorce their father, that's how bad it got."*
	P4/599	*"Sometimes I feel very guilty because I not asking* (brother) *very much about himself, but he is very understanding."*
	P8/75	*"My son's not a Christian so there has been tension and quite a bit of conflict there."*
Direct Care Responsibility	P1/491	*"You're just trying to get into their head. But by talking to him, I was trying to get into imagining; well I think*

		that I've done that now, how it must be for him. I've tried to analyse and reason with it."
	P5/225	*"We do our best to build up that self esteem again and to reassure him that we love him no matter what is wrong with him now."*
	P8/310	*"That's in God's hands now, I will pray about that one, what he wants me to say."*
Employment Responsibility	P3/73	*"Well for the first time in my life I had to go on social security, and that was all set up, which was awful really and a step you don't want to go down."*
	P9/629	*"I used to go with him to all his appointments, or be there and now I'm back at work full time I don't do that, so you know he can stand on his own two feet."*
	P1/73	*"When I applied for this job, I put in a comment about myself, and I said that I'm outspoken, I don't think that I'm outspoken to the point of being rude but I do think I'm honest."*

Supporting Quotes Corresponding with Main Category – Suffering as a Meaning Framework.

Category/ Subcategory	Reference	Supporting Quote
Suffering as Meaning Framework	P10/348	*"I think through having experienced very high highs and pretty low lows, I have got a good understanding of what the human condition is."*
Cause of Psychosis	P4/136	*"I think that he must have suffered quite a lot, because the culture was different, the language was so different and it's such a shock."*
Perspective on Others.	P5/383	*"There is one element of psychosis that for want of a better phrase is very religious, and that's in people's minds of course when you say that you are a Christian and that you are committed. Now I don't know what that factor is. I'd like to know, its something that I might study."*
	P9/203	*"I found it very difficult looking after dad because you know, he just believed that you lived and then you died and he was very anti religion and didn't want anyone gushing around him or anything like that."*

Catalyst for Strength	P10/328	*"I think that for me and I believe for other people as well, negative experiences, or very challenging experiences or very difficult times are associated with the most intense growth."*
Suffering as a Trial	P9/139	*"I actually do think it is really, thinking about it because so many surreal things have happened to me, unbelievable things have happened."*

Category/ Subcategory	Reference	Supporting Quote
Negotiating Mental Health Services	P6/131	*"It's more like you are not right when you talk about it, you must be crazy and especially it is quite funny that you are caring for somebody who is considered to be crazy and so you kind of question your sanity and I think that has influence, a quite negative influence on it.*
	P2/198	*"It irritates me, and I feel that I am wasting my time with them really, you know? They look at me and they say, oh you know she is the cause of it"*
Distancing Services from God.	P8/726	*"I went to see him (son) once on the ward, he was all contorted, his body was all contorted, it was awful and he was falling off the bed and the doctor was laughing and saying don't worry about him it's quite normal, we can give him something for that. I says he won't want anything, don't give him any tablets just willy nilly."*

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