**PROTOCOL: Nurses’ knowledge about Palliative Care in long-term care facilities for older people: a scoping review**

**INTRODUCTION**

# The Organisation for Economic Co-operation and Development (OECD) indicates that in developed countries, an average of 3 out of 10 citizens over 65 are living in long-term care settings (OECD, 2020b). These long-term care settings have also observed an increased need for beds and employed nurses over the past 15 years. Long-term care settings for elderly people describes a diverse range of facilities including, but not limited to, nursing homes, assisted living, retirement homes and care homes. These settings provide consistent and ongoing skilled nursing care to patients, meeting both medical and personal needs.

# In Republic of Ireland, from 2011 until 2016 nursing home residents older than 65 increased by 9.4%, meaning that 78.3% of this entire demographic resided in nursing homes (Central Statistics Office, 2016). The admissions from specialised Palliative Care services to long-term care settings increased the burden on these facilities (IHF & HSE, 2017). Over a quarter (26%) of deaths in the Republic of Ireland occurred in long-term care settings (HSE, 2019) and those settings are likely to become the primary location of death for elderly people in the future (WHO, 2010). An Economic and Social Research Institute report (ESRI, 2017) predicts that the demand for long-term care settings will more than double by 2030 (54%), and that the demographic of people over 65 will increase by 1.6 million in 2051. These predictions, if true, will create enormous challenges for providers and regulatory authorities (ESRI, 2018).

The World Health Organisation describes Palliative Care as a person-centered, comprehensive approach that enhances quality of life (QoL) in patients, and families of patients, who are living with life limiting conditions. Palliative care enhances QoL through early intervention, management of social, psychological and physical symptoms, and bereavement support (WHO, 2004). The term “geriatric palliative care” is now used to describe specific challenges that population aging represents, namely increased comorbidities and complex care needs (Voumard *et. al*, 2018) these include, but are not limited to, frailty, dementia, cardiac and renal failure, chronic obstructive pulmonary disease, dysphagia, polypharmacy, poor nutritional and hydration (Ersek & Carpenter, 2013; HSE, 2019). Non-malignant, chronic, progressive conditions require holistic, comprehensive, person-centered care and adequate end of life support (IHF, 2002; WHO, 2004; HSE, 2008). This topic emerged as a priority in society and a public health problem.

COVID-19 pandemic exposed various weaknesses in long-term care settings for elderly people. Devastatingly, in Europe, 40% of total deaths from COVID-19 happened in these places (EIP on AHA, 2020) demonstrating the need for adequate resources to provide acceptable end-of-life care and a requirement for better policies and guidelines to deal with unexpected events (Gilissen *et. al*, 2020). The European Commission concluded that 40% of total deaths COVID-19 related occurred in long-term care settings, highlighting the need for support, resources, and training to the healthcare professionals (EIP on AHA, 2020).

The role of nurses in long-term care settings is described as complex, demanding the understanding of several pathologies, needs and behaviors, conducting technical procedures, exerting clinical judgment, assessing needs, improving communication, risk assessing and managing – nurses often have leadership and management roles (CNA, 2013; McCloskey et al., 2015; CNA, 2020). In 2016, 40% of transfers from long-term care to acute settings were unnecessary (cost of USD 18 billion) and half of the harm occurring in long-term care was avoidable; this data reinforces the urgent need for targeted training, education and clinical governance in those settings (OECD, 2020b). Nurses’ knowledge is considered a corner stone of nursing practice as raises awareness and accountability, contributes to safety and quality of care, enhancing residents’ quality end-of-life, respecting their wishes and facilitating bereavement process for families (Fukada, 2018). The predictions of increased deaths in coming decades, flags the urgency to acknowledge the skills and knowledge of the nursing staff in such healthcare settings towards end-of-life.

**RESEARCH METHODOLOGY**

 A scoping review is a research methodology that aims to map concepts and synthesise information across a field or topic of study (Arksey & O’Malley, 2005). A scoping review was determined to be the most suitable methodology considering that the objectives of this study are to descriptively map important concepts on nurses’ knowledge about Palliative Care in long-term care facilities for older people. These concepts include key definitions used, barriers and contributing factors to success, possible knowledge gaps; map available evidence and focus of study; to identify programmes and strategies implemented and its outcomes; and to provide guidance for further research - to archive that, it is necessary to create strategies to disseminate the results (Munn *et al*., 2018; JBI, 2020; Pollock *et al.,* 2021).

This scoping review will follow the methods outlined in Joanna Briggs Institute’s scoping review chapter (JBI, 2020). The selection process outlined below will follow the recommendations in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) checklist and mapped using the PRISMA flow diagram to summarize the identification, screening, eligibility and inclusion of sources.

First, this protocol has predetermined the methods and objectives of the review to minimize bias. The protocol will be uploaded to Figshare before any searching or screening takes place.

Next, the research question, Nurses’ knowledge about Palliative Care in long-term care facilities for older people, is clearly stated in the title and will inform the eligibility criteria. The eligibility criteria follow the JBI Population, Concept and Context (PCC) framework. In this scoping review nurses are the population; Palliative Care is the important concept under investigation; and long-term care settings for older people is the context. All study types, primary and secondary, will be included to provide a broader perspective.

Third, a comprehensive search strategy will be developed in consultation with an information retrieval specialist. An example of this search strategy has been tested via the Medline (Ovid) database and is available in Appendix 1. This search strategy will be adapted for use in multiple databases including: MEDLINE (Ovid), EMBASE (EsbscoHost), Cumulative Index to Nursing and Allied Health Literature (CINAHL), CENTRAL, the Cochrane Library and sources of grey literature including Grey Literature Report and OpenGrey. There will be no limits applied to the database search to language or date of publication.long-term

Fourth, studies located via the search will be carefully documented and exported to EndNote. In Endnote duplicates will be removed and all remaining studies will be exported to review software Sysrev.com for screening. Two screeners will independently assess the eligibility of studies based on title and abstract and following the inclusion/exclusion criteria described below:

• Participants – nurses, all ages and gender identification. Excluding other healthcare professionals, family members and significant ones, volunteers, or other stakeholders.

• Concept – Palliative Care and synonyms to be used as search keywords. Those keywords may further be refined as is expected an increased awareness and understanding of concepts. Including all countries, cultures, and socio-economical levels.

• Context – long-term care setting for older people, excluding data from other healthcare settings (as ICU, acute care, community, and others).

A third reviewer will consolidate any conflicts between screeners.

Fifth, all included studies will be assessed at full text and the key information of the identified relevant sources of information will be extracted. This information includes:

1. Author/s

2. Year of publication

3. Country of origin (where the source was published or conducted)

4. Aims/purpose of study

5. Population and sample size (if applicable)

6. Methodology

7. Outcomes

8. Main findings (related to the scoping review question)

Finally, as this is a scoping review, the purpose is not to assess effectiveness of interventions. Therefore, the evidence located will be described narratively. Each included study will be described alongside their methodologies and a summary of the aims, outcomes, and findings.

The researcher will then map occurring concepts, characteristics, outcomes and their frequencies; and potentially identify gaps in knowledge. A table and diagram including the PCC elements and other relevant findings will be used to visually provide report findings.

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**APPENDIX 1 - MEDLINE ALL (Ovid) Search strategy**

MEDLINE ALL (Ovid) Search strategy

Tested on 12/02/2021 at 12:13 GMT

|  |  |  |
| --- | --- | --- |
|  | **Searches** | **Results** |
| 1 | Nurses/  | 39864  |
| 2 | Nurse\*.ti,ab.  | 283179  |
| 3 | Education, Nursing/  | 33031  |
| 4 | or/1-3  | 321685  |
| 5 | Palliative Care/  | 55523  |
| 6 | Terminally Ill/  | 6594  |
| 7 | Terminal Care/  | 28858  |
| 8 | palliat\*.ti,ab.  | 78250  |
| 9 | (terminal\* adj4 care\*).ti,ab.  | 3404  |
| 10 | (terminal\* adj4 ill\*).ti,ab.  | 7784  |
| 11 | (terminal\* adj4 disease\*).ti,ab.  | 3053  |
| 12 | Incurable.ti,ab.  | 11861  |
| 13 | (dying or death or bereave\*).ti,ab.  | 754842  |
| 14 | terminal\*.ti,ab.  | 473309  |
| 15 | ("End of life" or "End-of-life" or "EoL care" or EOLC or "end-stage disease\*" or "end stage disease\* or end-stage illness" or "end stage" or "advanced disease\*" or "Comfort care" or "Support\* care" or "Hospice care" or "Compassionate care" or "Limited survival" or "Critical\* ill\*" or "Life limit\*").ti,ab.  | 189638  |
| 16 | or/5-15  | 1454204  |
| 17 | Long-Term Care/  | 26363  |
| 18 | Homes for the Aged/  | 14173  |
| 19 | Nursing Homes/  | 35601  |
| 20 | Housing for the Elderly/  | 1633  |
| 21 | Assisted Living Facilities/  | 1430  |
| 22 | (Home adj4 (Geriatric or elderly or "old people" or "old person\*" or aged or senior or older)).ti,ab.  | 7907  |
| 23 | (Facility\* adj4 (Geriatric or elderly or "old people" or "old person\*" or aged or senior or older)).ti,ab.  | 940  |
| 24 | ("homes for the aged" or "residential home\*" or "residential facilit\*" or "nursing home\*" or nursinghome or convalescent).ti,ab.  | 40354  |
| 25 | or/17-24  | 89006  |
| 26 | 4 and 16 and 25  | 793  |