

Committee for Health Inquiry – Review of access to palliative care services

We are submitting this response to the Committee for Health Inquiry on behalf of the All Ireland Institute of Hospice and Palliative Care (AIIHPC) Psychological, Social and Spiritual Care Research and Special Interest Group.

The AIIHPC Psychological, Social, and Spiritual Care Research Group was set up in 2023 to bring together experienced and early career researchers, clinicians, users and carers from the island of Ireland to develop, promote and implement practice-changing research. Membership includes people from universities, hospice and palliative care organisations, care homes, charities, regulatory bodies, and other organisations who are committed to developing and delivering best practice in hospice and palliative care. By working together, the group mentors, nurtures, engages and supports, a more inclusive and collaborative approach to research on psychological, social and spiritual care, in order to generate the evidence needed to change practice, including, multi-site clinical-academic studies. Group members are currently engaged with multiple studies on a range of psychological, social, and spiritual needs within hospice and palliative care, including a recent national survey focusing on spiritual and psychological need, and a focus group with people of lived experience of using palliative care services.

EVIDENCE

Survey of palliative care workforce across island of Ireland

Our working group conducted a research study (unpublished) with data collection in August/September 2024. The research aimed to explore current practice and need in responding to and delivering spiritual and psychological support within palliative and end of life care services.

The research involved an online survey, circulated to AIIHPC members. There were 151 responses to the survey, from health and social care professionals across the island of Ireland with a patient/family carer-facing role in a palliative care setting (hospice, hospital, community).

Respondents were from a variety of disciplines reflecting multi-disciplinary teams across palliative care settings (e.g. nurses, social workers, OTs, chaplains, psychologists doctors, dietitians etc). The majority (52%) were experienced clinicians, having worked in palliative care settings for more than 10 years. The vast majority (72-81%) of the respondents were either very frequently or frequently involved in assessing patients' and family/carers' spiritual or psychological needs.

Selected findings:

Spiritual support

- The majority of respondents (88%) reported that they had rarely or never received training focused on spiritual care
- A large proportion of respondents (44.4%) reported limited access to spiritual care services as being a main challenge for delivery of spiritual care in palliative care.
- Other key challenges included lack of time (42.4%), uncertainty about support options (29.8%), and uncertainty about how to identify spiritual needs (25%)
- When asked what resources could help to address spiritual needs more effectively among patients and their family/carers, the majority of respondents (69.5%) reported 'more training in how to identify and address spiritual needs'. Training needs identified included;
 - Caring for oneself
 - Practical skills to address spirituality
 - Skills to identify and assess spiritual need
 - Better understanding of spirituality and religion
 - Greater awareness of culture and those who may feel excluded or ostracised
- Other resources identified included 'additional staff with expertise in spiritual care' (51.7%), and 'more time to spend with patients' (46.4%),

Psychological support

- The majority of respondents (74%) reported that they had rarely or never received training focused on psychological care
- Only a minority of respondents assessed patient or family carer's psychological needs using either a formal screening instrument (14.5%) or clinical interview based on diagnostic criteria (6%), as recommended in NICE clinical guidelines
- If psychological needs are identified, only a minority (37.8%) of respondents would refer to a mental health specialist (psychologist or psychiatrist) on the team. Other referrals are to a non-mental health professional, or external.
- The majority of respondents (65.6%) reported limited access to psychological services as being a main challenge for delivery of psychological care in palliative care.
- Other key challenges included lack of time (46.4%), uncertainty about treatment options (39%), and uncertainty about how to identify psychological needs (25.8%)
- When asked what resources could help to address psychological needs more effectively among patients and their family/carers, the majority of respondents (70.2%) reported 'additional staff with expertise in psychological care/mental health'
- Additionally, the majority of respondents (67.5%) reported a need for more training in how to identify and treat psychological needs. Training needs identified included;
 - Training on assessment and identification of psychological needs
 - Knowing when to refer and who to
 - Signposting to Support services
 - Creating communication and conversations
 - Mental Health engagement
 - Support in dealing with grief and loss

Focus Group Interview with Users and Carers

A focus group was held in October 2024 with nine people with lived experience of living with advanced disease or had experience of a family member dying of advanced disease to explore their thoughts and ideas on the psychological, social and spiritual support needed for people and families receiving palliative care support. Attendees were Voices4Care members from across the island of Ireland.

The findings showed -

The participants strongly believed that psychological, social and spiritual support was as important as good physical symptom management, but this was not always recognised by palliative care teams.

The participants recognised their own needs, and valued having access to spiritual, social, and psychological support within palliative care. However, often specialist staff or the resources required were not available and this caused distress to them and to their loved ones.

Participants acknowledged that each person might express these often less visible needs in a variety of ways, and these needs and their priority might change at different stages of their experience, for example, when they or their family member were told they had an incurable disease or when the reality of death was imminently approaching.

Understanding and responding to each person's needs requires careful assessment throughout the experience of living with advanced disease and the reality of facing death.

Spiritual, social and psychological support are important not only for the person receiving palliative care but also for the family/caregivers during this time and after their loved one has died.

RECOMMENDATIONS

The evidence provided is an up to date understanding of the workforce planning and development needs in palliative care settings across the island of Ireland. Based on this evidence and through discussion among our expert group, we submit the following recommendations to ensure adequate access to psychological and spiritual care.

I. *Recognition of the importance of psychological, social and spiritual care*

The WHO (2020) defines palliative care as “*an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual*”.

Psychological and spiritual distress are recognised as integral components of holistic palliative care, for example, when we consider how they contribute to Dame Cicely Saunderson's concept of ‘total pain’. The AIIHPC Psychological, Social and Spiritual Care Research and Special Interest Group was formed from recognition that psychological, social and spiritual wellbeing have not been prioritized in the delivery of palliative care across the island of Ireland, including in NI. As a working group, we would like to see a greater recognition of the importance of psychological, social and spiritual care within regional policy.

II. *Workforce planning- appropriate staffing of mental health and spiritual care specialists*

The evidence reported indicates a lack of access to specialist mental health and spiritual care resources across palliative care settings in NI. There is an urgent need for workforce planning to ensure adequate staffing of specialists with the competencies required to manage the severity and complexity of emotional and spiritual distress encountered in patients/carers towards the end-of-life. Specialists in psychological and spiritual care (i.e. psychologists and chaplains) also provide essential consultation, supervision, and education to other staff, thereby ensuring a robust stepped model of care, as recommended in NICE clinical guidelines (2004; 2019).

Minimum staffing levels for mental health and spiritual care specialists should be set and aligned to an evidence-based WTE per population, as stipulated in international guidelines and the new ROI adult palliative care policy. This is required across palliative care settings, to ensure timely support can be provided in the individual's place of care. Core funding of specialist staffing should be provided for hospices and other non-statutory organisations, as appropriate.

III. *Development of evidence-based pathways*

The evidence would indicate a lack of evidence-based pathways to screen, assess and manage emotional and spiritual distress, both within and across palliative care settings. Respondents in our research indicated uncertainty in how to identify distress, and uncertainty regarding the options for internal/external onward referral.

Aligned to the need for greater specialist resource, there is a need to invest in the development of evidence-based pathways which allow for emotional and spiritual distress to be identified early and alleviated by a clinician working at the appropriate level of the NICE stepped-care model.

IV. *Workforce development- formal training in psychological and spiritual care*

The NICE clinical guidelines (2004; 2019) stipulate that the majority of psychological and spiritual needs in palliative care settings should be met by non-specialists. Broader guidance also recognises the importance of all staff having psychological or spiritual competencies, e.g. the Marie Curie Spiritual and Religious Care Competences for Specialist Palliative Care. Our research indicates that clinicians are not currently following evidence-based clinical guidance in either identifying need or knowing how/when to refer on for more specialist support. A workforce development priority is to ensure non-specialists receive formal training in how to deliver psychological and spiritual care

which is evidence based and encompasses cultural competencies. The majority of respondents in our research reported having received no formal training.

The respondents in our research were largely experienced clinicians, which indicates a need to not only optimise higher education curriculum design to ensure newly qualified staff have the competencies required, but to also ensure opportunities for CPD in providing psychological and spiritual care are provided to existing staff within the workforce. Investment in more specialist staff will help facilitate more training opportunities, and ongoing support. However, it is also essential that psychological and spiritual needs are prioritised at an organisational level, with staff supported with time to attend training.