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An Exploration of Specialist Palliative Care Nurses' Experiences of Providing Care to Hospice Inpatients from Minority Ethnic Groups—Implication for Religious and Spiritual Care

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Abstract: The aim of this research study was to gain an understanding of nurses' experiences of providing care to patients from minority ethnic groups within the specialist palliative care inpatient unit of an Irish hospice. Five nurses working in a hospice inpatient unit with experience in providing care to patients from minority ethnic groups were interviewed using a hermeneutic phenomenological approach. Analysis of the data resulted in the emergence of two distinct constructs, "encountering a landscape of diversity" and "negotiating this landscape", each one comprising three themes. Findings relating to religion and supporting patients' religious needs were dominant in four of the six emergent themes—death and dying, acceptance, feeling their way, and being resourceful. The findings presented in this paper highlight the personal and professional challenges facing nurses when providing care in the context of religious diversity. In addition, participants' descriptions of their endeavours to negotiate the challenges in the context of these differences are identified. By applying these findings in practice, healthcare professionals hold the potential to positively impact the quality-of-life of patients, their families, and their experiences of hospice care in Ireland.

Keywords: spirituality; spiritual; spiritual care; religious care; palliative care; health

1. Introduction

Increases in immigration since the 1990s means that healthcare professionals working in hospices in the Republic of Ireland (ROI) are encountering increasing numbers of patients from ethnic backgrounds that differ from those of the healthcare professionals. The resultant presentation of differing cultural beliefs and values, and religious affiliation can be an unfamiliar challenge [1]. Although death is a universal experience, individual beliefs and practices regarding illness, death and dying vary across ethnic groups and therefore expectations of hospice care in this regard are likely to vary [2]. Although the recognition and facilitation of ethnic diversity is central to palliative care policy in Ireland [3], there is little information about nurses' experience of this, and whether or not challenges exist in practice. This situation is reflected internationally where there is a dearth of research focusing on nurses' experiences of providing care to patients from minority ethnic groups within hospice specialist palliative care inpatient units.

2. Background

There has been a steady increase in immigration in the ROI since the 1990's and this is a major contributing factor to a broadening of ethnic and religious diversity. The extent to which Ireland is now ethnically diverse is reflected in the latest census, which shows that Ireland has moved from a mostly homogenous population [4] to one where non-Irish make up 12% of the population [5]. The particular spiritual and religious needs of ethinically diverse patients in healthcare in ROI has received little attention, although small localised studies have identifed gaps in service provision, with patients leaving the hospital situation feeling distressed because their religious and spiritual needs may not have been met [6]. Ethnic groups share characteristics such as culture, traditions, religion and language which contribute to their individual or group's identity [7]. The heterogeneity of this section of society in the ROI is reflected in the estimate that over 199 nationalities are represented and 182 languages spoken [5]. Africans, Eastern Europeans and Asians constitute the largest new ethnic groups in the ROI [5].

The most common religions outside of RC are now other Christian religions (including Apostolic or Pentecostal Church of Ireland; Anglican; Presbyterian and Episcopalian), Muslim (Islamic) and Orthodox (Greek, Coptic, Russian) [8]. There are also rising numbers of Hindus [8]. The religious affiliation of the majority of people in ROI is Roman Catholic (RC) [8], and as a result it has also been found that nurses sometimes feel ill-equipped to deal with the needs of spiritual and religious needs of patients from other religious which would be considered minority religions [9]. Additionally within palliative care religion and religious beliefs can influence preferences for management of symptoms, sometimes adversely [10]. For example some rreligious beliefs can lead to the rejection of medication to manage symptoms causing practical and ethical challenges for staff [10,11]. In the growing diversity of the ROI, staff face unfamiliar practices and customs which can make them protective of other patients [11] and lead to uncertainty, apprehension, discomfort, and fear of causing offence [12]. Although the particular spiritual and religious needs of ethnically diverse patients in healthcare in the ROI have received little attention, small localised studies have identified gaps in service provision, with patients leaving the hospital situation feeling distressed because their religious and spiritual needs may not have been met [6].

One national study reported in 2011 [13] suggested that the provision of spiritual care in ROI is firmly enshrined in RC tradition and requires development to meet the needs of the ethnically and religiously diverse population. However prior to this and to address potential gaps in service provision and to equip health professionals with an adequate information and resources to support ethnic minorities in ROI, the national health board in ROI, the Health Service Executive (HSE), developed a set of guidelines [14]. These guidelines are recommended to be available to staff on all clinical areas. The extent of theuse of these guidelines is unknown. At the same time the national provision of chaplaincy services is under review [15]. In order to meet the religious needs of patients from minority ethnic groups it has been recognised that factual knowledge is required [12,16] in addition to education and training [11,17–19]. For healthcare professionals involved solely in the provision of palliative care, the aforementioned issues are of particular relevance.

Palliative care is an approach that aims at improving the quality-of-life of patients and their families facing the problems associated with life-threatening illness. This is achieved through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems [19]. Hospice is a place of care, whose core activity is limited to the provision of palliative care [3]. Hospice-based inpatient services are offered to patients when their illness is at an advanced stage, for management of complex symptoms, psychosocial problems or for end-of-life care; care when death appears to be imminent (National Clinical Programme for Palliative Care (NCPPC) [20]. Anecdotally there are an increasing number of patients from minority ethnic groups being admitted to Irish hospices. While death is a universal experience, individual beliefs, feelings and practices in regard to this experience vary widely

across different cultures and religions [21]. In this context, nurses in the ROI may encounter challenges in their endeavours to provide care in line with the needs of various minority groups.

While "recognising and facilitating cultural diversity" is a key recommendation of palliative care policy in the ROI ([3], p. 45), there is no evidence of how this is experienced by nurses working in the specialist palliative care inpatient setting. This may be in part be attributed due to the relatively homogeneous nature of Irish society, whereby there was little need to examine ethnic and cultural considerations in the context of hospice care in Ireland. However, as argued by Van Doorslaer & McQuillan [22], this appraisal is becoming increasingly necessary given the aforementioned growing diversity.

There is a dearth of international research related to nurses' experiences of providing care to patients from minority ethnic groups within the specialist palliative care inpatient setting with no study emerging from Ireland so far. One Irish study was identified which explored interdisciplinary specialist palliative care professionals' experiences of providing care to Irish Travellers [18], who are identified as a distinct ethnic minority in ROI [23], but inpatient hospice nurses were not represented in this sample.

In order to address these gaps, and learn more about nurses' experience, the focus of this inquiry was to explore nurses' experiences of providing care to patients from minority ethnic groups within the specialist palliative care inpatient setting in the ROI.

3. The Study

3.1. The Aim

The aim of this study was to gain an understanding of nurses' experiences of providing care to patients from minority ethnic groups within the specialist palliative care inpatient unit of an Irish hospice.

3.2. Method

The research problem was addressed using a hermeneutic phenomenological approach, guided by the philosophy of Hans-Georg Gadamer (1900–2002). Hermeneutics provides an approach to inquiry that is very suited to the philosophy and art of nursing as it concerns understanding the uniqueness of individuals and explores their ascribed meanings of events and relationships [24]. According to Moules ([25], p. 24), while there are many "voices" of hermeneutics, ultimately the decision as to which philosopher guides the practice of hermeneutics lies in selecting the philosopher which best suits the researcher's beliefs. In descriptive phenomenology the phenomenon is believed to be reality; an absolute truth that exists as an essence and can be described [26]. Husserl's belief that essences can be extracted from experiences without consideration of context was inconsistent with the aim of this study. Additionally, the primary researcher is as a specialist palliative care inpatient unit nurse, with experience of the phenomenon under investigation, and therefore it would have been difficult to bracket their own lived-reality while undertaking this study, as is espoused by Husserl. While Gadamer's philosophy was found by the researcher to be closely connected with the work of Heidegger, stylistically and substantively the difference between their two modes of thought is the difference between a meditative (Heidegger) and a dialogical (Gadamer) thinker [27]. Based on the belief that communication through language forms an integral part of conveying meaning and understanding for nurses, it was Gadamer's emphasis on the universality of language, as relevant among and across persons giving care, which resonated most with the researchers [28]. Consequently, the researchers chose to undertake an interpretive approach guided by Gadamer's philosophy.

Data collection consisted of two unstructured interviews with five specialist palliative care inpatient unit nurses, recruited from one ROI hospice. During their interviews participants told stories of the patients and families they had cared for from various minority ethnic groups, namely African,

Asian, Eastern European, Irish Travellers and Roma. Overall, 10 interviews were carried out over a 6-week period.

3.3. Ethical Considerations

Ethical approval was granted by the Local Research Ethics Committee. Nurses were informed about the study and invited to take part by a local gatekeeper in practice. Attendance at the interviews was voluntary, and those wishing to take part contacted the researcher directly to make arrangements. All participants were consented and interviews took place in a private, quiet room at the hospice site.

3.4. Method of Data Analysis

Thick description which accurately communicates participants' experiences is key to phenomenological studies [29]. For the purpose of this study, a four-step data analysis method, developed by Fleming *et al.* [30] was used to analyse textual data.

3.5. The Findings

Analysis of the data resulted in the emergence of two distinct constructs: "encountering a landscape of diversity" and "negotiating this landscape", each comprising three themes. Within the former construct, the following three themes emerged: death and dying, family systems, and language barriers. The latter construct also revealed three themes: acceptance, being resourceful, and feeling their way. Together, these constructs and their related themes represent not only nurses' descriptions of the differences they encountered when providing care to patients from minority ethnic groups within the hospice inpatient setting, but also their endeavour to negotiate challenges encountered in the context of these differences. The findings revealed that religion and supporting patients' religious needs were dominant in four of the six emergent themes; death and dying, acceptance, feeling their way, and being resourceful.

3.5.1. Death and Dying

The significance of religion in death, and the dying experience, was acknowledged by nurses, as reflected in the following comment:

> "When it comes to death...religion plays such a huge part of it." (Participant no. 1). ([31], p. 39)

Thus, notably, facilitation of religious practices and death rituals were considered to be an important part of their role as a specialist palliative care inpatient unit nurse. For nurses in this study, feelings of inexperience, unease and helplessness arose when encountering the unfamiliar, compared to the familiarity they expressed with the religious needs and death ritual needs of patients in the ROI.

> "We get so used to how an Irish death works as such...but you have so much more to consider when you have somebody from a different religious background." (Participant no. 1). ([31], p. 39)

> "My experience is mostly with Catholics. I would have some experience with Muslim religion, Hindu religion...but I probably didn't mind them in the terminal stage of their illness, so...I wouldn't know exactly what to do when they die." (Participant no. 5). ([31], p. 39)

> "....our Muslim gentleman, he would be having prayer a lot during the day, normally they would pray five times a day. Sometimes you feel...any time before you go in the door might think 'will he be praying'? Or ...'should I go in'? Or...'will I be disturbing him'?...that's the difference. So, normally if it's an Irish patient, say a Catholic patient, even though they are saying prayers they will probably interrupt for the nurse. If you go in and they are saying their rosary, they will probably stop praying, for a minute, but this gentleman, he would probably send you back." (Participant no. 5). ([31], p. 39)

> "...it is going to be very loud when he dies...normally when we hear somebody wailing our instinct would be to help them and to stop it, but we can't stop this, in this event. I don't think I'd like to be there." (Participant no. 2). ([31], p. 40)

In keeping with this latter quote, which alludes to the physical presence of different religious practices and death rituals on the unit, this was also noted by a subset of participants in terms of its perceived effect on other patients:

> "...they had a six foot tall statue of the Virgin Mary sitting at the bottom of the bed. It's very difficult for the other patients in the room to deal with things like that. The constant prayers, the rosary beads...and just the volume of people coming in, with the constant prayers, it gets quite loud and it can be intimidating for some of the other patients" (Participant no. 1). ([31], p. 39)

> "...we have to think about our other patients, because obviously it's not the norm for them as well. What actually might be challenging if he did pass away tonight, is three rooms down from him is a gentleman with young children coming in and they are staying overnight. I couldn't think of anything worse than if it all just happened on the same night." (Participant no. 2). ([31], p. 40)

In the context of the dominant principles of palliative care such as pain and symptom management, there was a perception amongst participants that religion played a role in patients' and families' beliefs regarding the use of medication to manage symptoms. The following comments describe the tension nurses experienced when these beliefs did not correspond with their own professional values to relieve suffering and promote comfort:

> "...when we started a syringe driver for her unfortunately the lines were cut a few times, they just didn't want it...I suppose it's your belief...they had it in their head that morphine was going to speed up her death and you can't do that, you have to let it happen naturally, when God is ready for her to go. I found that hard." (Participant no. 1). ([31], p. 38)

> "They were quite curious about morphine. It's quite challenging to let them know what the intention of the medication is. It's so difficult to treat those people...I find that hard to see them, because...we have comfort measures as a priority. And of course, it's nice to see them controlled, their pain...their symptoms, so they can have a quality-of-life." (Participant no. 4). ([31], p. 38)

In keeping with this finding, there was a perception amongst nurses that patients could potentially suffer as a result of their religious beliefs:

> "...they were very anti-opiate. Every time I went in I saw pain etched on her face and yet they'd say 'no she has no pain', 'doesn't need any opiate, we're not having any morphine'. We did organise meetings with the family to explain the role of opiate and that we wouldn't be sedating her unnecessarily and we wouldn't cause all these side effects they were concerned about, but they were very against it. I think she probably could have had a more comfortable death had we been able to get in." (Participant no. 1). ([31], p. 38)

3.5.2. Acceptance

Although it was evident from participants accounts that challenges arose for nurses in the context of encountering religious diversity when providing care to patients from minority ethnic groups, and their families, the theme of acceptance revealed that care offered but not imposed was seen as an important feature of providing care to patients from minority ethnic groups, as was accepting and respecting their autonomous choice as to their level of engagement in palliative care. This was described by one nurse as follows:

> "That's their belief. You can only advise them and say that we are here to help...we wouldn't go against it, it's entirely up to them . . . with medication, we just give them the choice." (Participant no. 3). ([31], p. 43)

3.5.3. Feeling their Way

In the context of meeting patients' religious needs, a recurrent theme across participants' accounts was that they were often feeling their way, acting slowly and carefully in the presence of uncertainty or the unfamiliar. For one nurse, this was described in terms of exerting caution so as not to cause offence:

> "...you always have to think to be more cautious...because you're not very familiar. You wouldn't want to offend them or anything. You need to take your time, go slowly." (Participant no. 5). ([31], p. 48)

3.5.4. Being Resourceful

In light of the broadening of ethnic diversity in Ireland, participants noted the need for nurses to become more knowledgeable as to the different religions groups they will continue to encounter. This was described by one participant as follows:

> "We are coming across more people coming from abroad and different backgrounds, different cultures, religions...it's time we knew...we need to know." (Participant no. 2). ([31], p. 44)

This was echoed by another participant in terms of the importance of having a prior awareness of patients' religious beliefs:

> "...you need to know the patient's beliefs, before you step into their world." (Participant no. 4). ([31], p. 44)

By way of preparing, and enabling, nurses to meet the religious needs of patients from minority ethnic groups and their families, all participants highlighted the importance of resources. The various resources available to participants within their organisation ranged from written resources, to the specific support received from community and hospice-based religious and spiritual representatives. While these were considered valuable in guiding nurses as to patients' religious beliefs, they were also considered in terms of their limitations: These were described by one participant as follows:

> " . . . we are using his Church, so he has his Imam...we are using them and they're guiding us in their cultural and religious beliefs. We speak to our chaplains here...they have a lot of experience. But they are not going to be the ones actually, on the day, they might not be here...so then what?" (Participant no. 2). ([31], p. 45)

> "[the intercultural guide [14] was good, because we went to it, photocopied it and put it in his chart so that when, in the event of something happening, it can be a guide for whoever is on. But I'd like somebody actually with experience of doing it, rather than just reading it out of a book. Like we look up all the information...for instance, our Muslim patient, in the event that he is dying...what are we going to do? No one actually has experience." (Participant no. 2). ([31], p. 45)

Furthermore, in light of the many variations of beliefs across different ethnic groups, and the degree to which individuals may or may not adhere to practices within their religion, one participant noted the significance of approaching the individual, using written resources only as a guide:

> "I would do a bit of background reading, but I suppose there are many variations of every religion...just because they're Catholic necessarily mean they want the last rites or candles, or prayers, or a cross at then end of the bed, and just because they are Muslim doesn't mean female staff can't go into the room. So I would generally have an idea of what their beliefs

> would be and then involve both patient and family to find out what they want, what they believe, what they want you to do or don't want you to do...it's just about finding out from them all the time." (Participant no. 1). ([31], p. 45)

In the context of the limitations identified, all participants noted the need for, and welcomed the possibility of, ongoing education and further training:

> "...with Ireland and the economic change we're seeing more of cultural diversity, there's definite need for ongoing education." (Participant no. 3). ([31], p. 45)

> "It would be great if there was some kind of study day or something...or if you could bring in different types of maybe, religious or community leaders. It could be so informal as well, couldn't it...I just sometimes wish we had more hands on [experience], like somebody who actually knows all about it." (Participant no. 2). ([31], p. 45)

4. Discussions

This paper reports findings relating to nurses' experiences of religious diversity when providing care to patients from minority ethnic groups within an ROI hospice. In the context of the personal and professional challenges facing nurses which were identified, these findings suggest the need for organisations to endorse, encourage and facilitate reflective practice activities at the ward level, as a means of supporting nurses in their endeavour to provide religious and spiritual care in line with patients' needs. Additionally, while resources were available to [14], and utilised by, participants in practice, a subset of participants highlighted the need for more "hands-on experience" specific to the religious needs of this patient cohort. Any such experience or education however, needs to take into consideration the competencies required for providing spiritual care in nursing as suggested by Van Leeuwen and Cusveller and his colleagues [32–34]:

- handling one's own beliefs;
- addressing spirituality;
- collecting spiritual assessment information;
- discussing and planning spiritual interventions;
- providing and evaluating spiritual care; and
- integrating spirituality into institutional policy.

At the same time, to focus solely upon the beliefs and needs of the minority ethnic and religious groups may cause marginalisation of the majority or be seen to minimize these [35]. Therefore, a cohesive approach to understanding patients' and families' spiritual and religious needs in a hospice setting is required. It was clear within this study that even the practice of religious rituals related to the dominant RC caused some discomfort. Nevertheless, the prevalence of the need for formal education in the study's findings is suggestive of an intervention which may serve to increase healthcare professionals' confidence when providing care to patients from minority ethnic groups within the hospice setting. For nurses in this study, input from religious and community leaders was identified as holding potential value for informing their content. Finally, these findings reinforce the importance of the integration of religion and spirituality in the planning of both undergraduate and postgraduate health care educational programmes in the ROI.

Application of these findings by healthcare professionals in practice holds the potential to improve the quality of religious and spiritual care delivered to patients from minority ethnic groups, thus positively impacting their quality-of-life and their experiences of hospice care.

Given the dearth of research in this particular field, some new and additional research is recommended to follow up from these findings and to determine whether or not nurses' experiences are universal or whether the emerging themes are generalizable outside of this ROI context. There is potential for comparative qualitative research in different sites, which could be further developed

into a large-scale survey that determines nurses' overall experiences. Specific themes identified in the study, such as encountering and navigating a landscape of diversity could be further explored using either qualitative or quantitative methods. The impact of spiritual and religious beliefs on patient and family experiences of hospice care and overall care outcomes might also be explored as well as the impact of targeted educational programmes aimed at reducing knowledge deficits in the field.

5. Limitations

In keeping with the phenomenological approach, a small purposive sample was used in the study. While this provides rich data about a topic that has been hitherto under-researched, the approach is subjective and not generalizable. It is hoped that what was learned from this study is transferable to other settings and that empirical research may follow to enlighten us further about this important area. It is also important to note that perspectives are culturally mediated and that the practice organisations concerned and wider cultural influences may have affected the perspectives of the participants in the study.

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Abbreviations

The following abbreviations are used in this manuscript:

CSO	Central Statistics Office
DOHC	Department of Health and Children
HSE	Health Service Executive
RC	Roman Catholic
ROI	Republic of Ireland

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