Nursing Strategies for Engaging Families of Older Immigrants Hospitalized for End-of-Life Care: An Australian Study

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Abstract

Background: Engaging with families of older non-English-speaking background (NESB) immigrants hospitalized for end-of-life (EOL) care can be challenging, especially when their cultures, lifeways, and family decision-making processes are unfamiliar to the nurses caring for them. Despite the recognized importance of family engagement when providing EOL care, the issue of ethnic minority family engagement has received little attention in the field. **Aim:** To explore and describe the strategies nurses use to facilitate engagement with families of older immigrant NESB patients hospitalized for EOL care. **Methods:** A qualitative descriptive approach was used. Data were collected via in-depth interviews conducted with 22 registered nurses recruited from 4 Australian health services. **Findings:** Using thematic analysis processes, 5 key strategies were identified: listening and understanding families, encouraging family members to speak first, dealing with angst, redressing naive views about the dying process, and managing intergenerational differences. Underpinning these strategies was a profound "will to engage" with the families and their cultural worldviews. **Conclusion:** Further cross-cultural comparative research is required to inform evidence-based policies, practice, and education on this issue.

Keywords

aged, cultural diversity, immigrants, family, engagement, nurse–family relationships, end-of-life care, hospitalization, Australia

Introduction

Hospitalization for end-of-life (EOL) care in the last weeks, days, or hours of life can be a stressful event for relatives of an older person, even more so if they are of an immigrant ethnic minority or "non-English-speaking background" (NESB). A key reason for this is that, irrespective of how long they have lived in their adopted country, immigrant families may view the acute hospital environment into which an ill loved one has been admitted as unfamiliar, "foreign," and even threatening (1). Moreover, people whose first language is not English and whose cultural world views (core cultural values and beliefs) are significantly different from those of their professional care givers often face a "double jeopardy" in terms of being misunderstood, having foreign normative values and beliefs imposed on them in distressing ways, and generally being at greater risk than are nonimmigrant patients in terms of receiving unsafe and poor quality of care (1-4). Thus, upon encountering the unfamiliarity of the hospital environment, the family's fears of and insecurities about "what lies ahead" and whether their loved one will be "understood," "safe," and "well cared for" risk being compounded, unless family members are assisted to interpret this unfamiliar environment in a culturally meaningful and reassuring way.

Families are widely regarded as the "principle source of support" for persons with an illness (5-9). However, family members themselves often need support from health-care personnel when their relatives are admitted to hospital (8,10-12). This need is especially great in the case of families of older immigrants when either they or their relatives lack sufficient English language proficiency, that is, are of an NESB and the level of health literacy otherwise needed to meaningfully navigate the health-care system and negotiate the care and treatment options that are proposed (10).

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Background

In the cultural context of Australia, family members of older immigrant NESB patients have often successfully assumed the primary care of their older relatives with a chronic illness over an extended period of time. Against this backdrop, hospitalization of an older relative for EOL care can stand as a disruptive event to the normalcy of family relationships, communication modes, and care models (13). This in turn can leave family members feeling dislocated from each other and socially isolated (13). Even when death is expected, when a loved one is admitted to hospital for EOL care, family members can experience a range of emotions, including fear, shock, frustration, guilt, worry, distress, anxiety, vulnerability, and helplessness (8,14,15). Thus, a care situation that was previously experienced as being relatively orderly, manageable, and socially supported may suddenly be experienced as chaotic, overwhelming, and isolating. It is at this juncture in the care trajectory (ie, from home to hospital care/from progressive chronic illness to actively dying), and where disruptions to normal family relationship processes begin, that nurses can play (and may be expected to play) a fundamental role in engaging family caregivers and supporting them to regain a sense of order, meaning, and manageability in the situation (10-12,16,17).

Over the past few years, the idea of patient and family engagement in health care has been variously depicted as "a critical part of a continuously learning health system, a necessary condition for the redesign of the healthcare system, the 'holy grail' of health care, and the next 'blockbuster drug of the century'"(18, p223). Despite patient- and family-centered care long being supported by local standards, policies, and guidelines and more recently by the World Health Organization (19), there is an acknowledged "lack of attention to identifying the processes associated with interventions nurses are offering patients and their families" (14, p37,20,21). In the case of processes associated with interventions nurses are offering older NESB patients and their families, there is an even greater lack of attention and systematic inquiry (10,22). To ensure positive outcomes of the EOL care trajectory, a deeper understanding is required of the strategies used by nurses to meaningfully engage families of ethnic minority NESB older immigrant patients admitted to hospital for EOL care and thereby help them to engage in and manage the dying process in a culturally meaningful and emotionally satisfying way.

Methods

The findings presented in this article derive from a larger study investigating the decision-making strategies used by registered nurses when caring for older immigrants of NESB hospitalized for EOL care, but which could not be considered within the scope of the original report (23). The study was approved by the Deakin University Human Research and Ethics Committee and the 4 Victorian health services at which participant recruitment and interviewing occurred. Full details of the larger study and its methodology (including interview questions) have been reported previously (23).

Setting

This study was conducted in the Australian State of Victoria (population 5.866 million), which has the second largest multicultural population in Australia. More than 26% of Victoria's population is born overseas in more than 200 countries, and more than 22% of its population speaks a language other than English at home (24). Of Australia's multicultural population, older NESB immigrants have higher rates of admissions and hospital bed utilization in the last year of life compared with the Australian-born population (25). In addition, it has been estimated that patients born overseas constitute almost one-third (32.1%) of those seen in specialist palliative care services Australia wide, highlighting the growing needs of this vulnerable population (26).

Sample

A purposeful sample of 22 registered nurses was recruited from 4 hospitals in metropolitan Melbourne and regional Victoria. Inclusion criteria were holding current registration as a nurse (division 1); practicing in a Victorian hospital; and provided care to older NESB immigrant patients aged 65 years and older admitted to acute care services for EOL care. As previously reported (23), of the 22 nurses recruited to the study, 11 worked in medical–surgical wards and critical care, 8 worked in acute palliative care, and 3 worked in the aged care sector. The majority (91%) of the participants were female, and of those who completed the demographic questionnaire, most (82%) had been in their current position more than 5 years (range: 1-20 years). Eleven participants indicated that they had undertaken postgraduate studies (postgraduate certificates [n = 3], postgraduate diplomas [n = 1], and master degrees [n = 7]), with 4 (20%) indicating that they had completed their highest professional qualification in the last 5 years. The final number of participants ultimately interviewed was determined by the point at which data saturation was achieved.

Results

Participants believed that nurses had a fundamental role to play in actively engaging the families of older NESB immigrant patients who had been hospitalized for EOL care. When prompted to explain the basis of this belief, participants revealed that it largely derived from their consolidated years of experience and observation that, because of often being closely knit as a family unit, family members of NESB older patients both wanted and needed to be involved in the care of their loved one. The following case was given as an exemplar of family members (including sons) wanting to be actively involved in the care of their loved one and how

nurses would "work around them" rather than family members being expected to work around the nurses:

> We had this Sunni Muslim lady from [name of country deleted] with cancer, very cachectic, had a huge tummy, dying. Now her three sons ... did all the care for that woman. She only had three sons and they were all married and the daughter-in-laws would come in—they had the full burkas so they were a very traditional Muslim family, but the boys did all the care. They carried her to the toilet, like carried her, they fed her. They were still very respectful of our interventions but they did everything for her.

In keeping with their beliefs that family members often wanted and needed to be involved in their care of their loved one, participants were eager to ensure that family members felt included and were encouraged to be actively involved in the direct care of their relatives:

> You involve them in the care. If you're in [the patient's room] doing mouth care, you encourage them [the family] to do that mouth care. If you've got a couple of daughters there and Mum is in the bed, you say, 'Do you want to help me do this wash?' Or if you've got sons with their father, the same thing: 'Do you want to help me?'

Data suggested that, in general, the participants used 4 key strategies to actively engage families of NESB backgrounds in EOL care, notably: "listening to and understanding the family," "encouraging family members to speak first," "ascertaining the family's decision-making model," and "dealing with angst," with the latter encompassing the additional substrategies of "redressing naive views about the dying process" and "dealing with intergenerational differences in values and beliefs about EOL decision-making and care" (Table 1).

Listening to and Understanding the Family

Critical to engaging families effectively was "facilitating good communication" with them, which involved paying close attention to and understanding what the family's needs and concerns were from their cultural perspective (which sometimes required the use of an interpreter).

Encouraging Family Members to Speak First

Participants believed that an essential strategy for effective communication aimed at engaging family members was encouraging them to "speak first" so that they would feel they could ask questions and be coparticipants in their loved one's frontline care.

Ascertaining the Family Decision-Making Model

Through their collective experience and the observations made over the years, participants had developed a deep awareness of the need to make careful inquiry about the nature of the family decision-making model that might be in play—including who, if anyone, was the preferred spokesperson for the family, how best to determine this, and how to approach that person once identified.

Dealing With Angst

A critical component of engaging with families involved recognizing that families could sometimes be "difficult" and that their difficult behaviors were often a sign of "angst," which participants tended to attribute to death anxiety and associated stress-related behaviors rather than "bad character." In light of this, participants believed that they had a fundamental advocacy role to play in ensuring that families were neither labeled nor stigmatized when exhibiting angst.

Redressing Naive Views About the Dying Process

Participants revealed that one of the greatest challenges they faced when providing EOL care to NESB older patients was dealing with family members (particularly those of younger generations) who had "a naive view about death and the dying process" and which sometimes emerged as a source of tension among family members. To counter these naive views and the tensions that sometimes arose, the nurses embarked on a process aimed at providing relevant information in a timely and sensitive way and thereby assist families to better understand the dying process and what to expect. This process encompassed 2 commensurate stages. The first of these was being mindful that the family would carry the experience of the death of their loved one into the future and for nurses to anticipate the questions they might have relevant to managing the dying process and subsequent death. The second stage involved nurses being "contactable" and "available" to provide family members with relevant information in a timely and appropriate manner to help them "make sense" of what was going on and to prepare for each stage of the dying process and the inevitable moment of death that would follow.

Dealing With Intergenerational Differences

Another challenge encountered by participants was dealing with intergenerational differences in values and beliefs about health care and about what should or should not be done when the patient's condition is deteriorating and death is imminent. These differences sometimes resulted in serious conflict, which nurses found daunting.

Discussion

The findings of this study contribute to a deeper understanding of the processes and interventions used by nurses to help establish, build, and sustain quality nurse–family relationships with families whose older NESB immigrant relatives

Table 1. Themes and Supporting Participant Statements.

Themes	Participant Statements
Listening to and understanding the family	"The first thing I'd do is try and understand that person, to know them a little bit. Ideally, I would do that with an interpreter … " "You need to be very careful and be able to have very good communication skills to facilitate that family communication … You have to be able to listen to all their beliefs … You have to be able to bring them on board with you – and have that quality to bring them on board with you – and lead them along the journey. Get them involved in the care and gather all that family information first … You need to understand the family's perspective. And where that person stood in the family is the main thing to understand."
Encouraging family members to speak first	"I've seen the ICU doctors do it with even standard English speaking patients is that they actually start the conversation with … 'Tell me about what mum or dad were doing six months ago. Tell me about what …' … and they actually encourage the family to speak first. Because they actually encourage the family to speak first it means that if there's any point along the way where the family isn't comfortable or needs clarification about anything, because they've spoken first, they're always happy to interrupt and ask a question. Other people actually start the conversation with 'We will tell you about what's happened' … which then leaves the family thinking, 'I'm here to receive information' not 'I'm here to ask questions or give information.'"
Ascertaining the family decision-making model	"I've learnt to be able to get to know the person, get to know the family, work out who's the significant person, who not to give too much information to, who we avoid and how much the person, the actual person, wants to know about their illness … Some ethnic groups, they don't want to know their diagnosis … and if that's part of their family and their cultural understanding, why would you force it upon someone?" "My approach has always been: 'Well, let's understand this person and how they want their care delivered to them.' … Do they want us to go through sort of a surrogate decision maker in their family? Someone they designate. When you find that out right at the beginning of their care … problems are far reduced."
Dealing with angst	"Ongoing communication [is pivotal]. I hate it if nurses label people as 'difficult' because actually they're not difficult; they're frightened or they're just distressed and they want to get answers. It's just acknowledging that this is an awful, awful time and that you will remember some things but you won't remember other things. It's okay to repeat and it's okay to ask us…. Families remember kindness and kindness transcends any cultural group, any ethnicity. Nonverbal kindness and your caring, that is everything. Whether it's putting a blanket on a shoulder or offering a drink, you don't need to say any words."
Redressing naive views about the dying process	First stage: "The one thing that's really important about a death, any death, is that it's something that that family's going to carry into the future with them…. Most families don't have that opportunity to experience [death] and quite often they don't know what to ask or what's going to happen." Second stage: "Having someone [the nurse] who they can contact and who could help them through the changes that happen. Someone [the nurse] who would [help them to] understand the nature of death—that you become sleepier, you spend more time in bed, you eat less, that that's all natural. So they [the family] wouldn't be traumatised by weight loss, changes in breathing." "[The role of the nurse] might be telling them about breathing—that it might be getting a little bit noisy but it's not making them uncomfortable; or it might be about pain or it might be about colour changes in the skin. Being able to honestly answer questions that the family have about what's happening and why it's happening and to actually be able to help them through it. I think to a lot of people death is very much related to what's on TV or 'Bang, bang you're dead.' They don't see it as a process which may take time. They see it as something 'Now you're here, now you're not.' They don't see that there's actually a time of passing."
Dealing with intergenerational differences	"Then their children, who are often the carers of these people, are adopting a more current sort of Australian values but also have that one foot in their traditional family values. You see the children quite torn often and sort of vacillating between things. Often I would meet sons and daughters and they would come across as 'We're not into that whole, you know, can't talk about death and dying thing … you have to shut it all away.'" "A lot of the migrant population seem to understand a lot more quickly that [no more medical treatment will help]…. A lot of them had [an] upbringing [where] for them … when your body stops, your body stops. A lot of them don't expect a lot to be done. But it's often very difficult for the next generation, like their children, because their children actually haven't had grandparents or seen other relatives die. So therefore they struggle with what their role is in all of this. Because quite often, if they haven't had older members of their family or a generation above their parents [die] then they actually really struggle with what their role is in all this…. They kind of think that their role is to push for everything that can be done, must be done, should be done. So I often find the children on one side really pushing that everything must be done and the parents sort of sitting quietly in the background going 'I'm not sure why we're doing all this.'"

have been hospitalized for EOL care. The strategies participants used to meaningfully engage the families of hospitalized NESB older immigrant patients were in keeping with the working definition of "family engagement" devised from Carman and colleagues (18) and encompassed giving timely and understandable information (eg, about the dying process, about what to expect, about care plans), ascertaining the family's knowledge and understanding of their and their loved one's value and beliefs (eg, finding out and understanding the family's needs, discerning the family's communication and decision-making model, responding to the needs of the family in an empathic, respectful, and culturally appropriate way), giving families encouragement and support (eg, encouraging family members to speak first and to ask questions, using an interpreter where necessary, being present and contactable, dealing appropriately with angst), and involving families (eg, making families feel included by encouraging and supporting them to be involved in the direct care of their loved one).

The strategies described by participants are consistent with those identified in the health professional literature as being conducive to fostering quality professional–family relationships, notably effective communication, providing emotional support, giving relevant information, and facilitating inclusion. The specific strategies that have commonly been identified by researchers include providing relatives with relevant information in a timely, "easily digestible" and sensitive manner (eg, about care and treatment plans, symptom management, and the dying process) and generally meeting family care givers' needs, for example, to be acknowledged, to have their values and beliefs respected, to be invited into the care and treatment process, to be "present," and to be given emotional support (7,10,11,14,17,18,27-32).

A notable finding of this study was the participants' positive attitudes toward the importance of including families in nursing care and the active steps they took to consciously and conscientiously engage families. This finding concurs with similar findings made by Benzein and colleagues who report that the supportive attitudes of nurses are "an important prerequisite for inviting and engaging families in nursing care" (6, p172) and James and colleagues (8) who report that the attitudes of professional caregivers are crucial to promoting effective interactions between professional and family (informal) carers.

A notable feature of the participants' attitude in the current study was that it was reflective of a "will to engage"—an attitude akin to Watson's theorized stance on "the will to care" (33). Watson makes the important point that unless the ideals of care and caring are translated into action, they risk being futile; she writes:

> The idea and value of caring is clearly not just a *thing* out there, but is a starting point, a stance, an attitude, which has to become a will, an intention, a commitment, and a conscious judgment that manifests itself in concrete acts (33, pp31-32).

Drawing on Watson's views, there is scope to suggest that the "will to engage" is likewise not just a thing out there, but a conscious stance that also has to become a will, an intention, a commitment, and a conscious judgment that manifests itself in concrete acts. Unless translated into action (such as exemplified by the participants in this study), the ideals of family engagement likewise risk being rendered futile.

Another essential feature of the participants' will to engage was their commensurate will to engage with "difference" (cultural diversity) and not to "other" the families of the older NESB immigrant patients in their care. "Othering" has been defined as "a process that identifies those that are thought to be different from oneself or the mainstream" (34, p253). In health-care contexts, othering (which can take the form of making over generalizations about culture and ethnicity, misusing "culture" in a stereotypical way to explain individual behavior, and the use of disguised racism to explain differences in health practices) is problematic since it can result in people of ethnic minority backgrounds being dominated, subordinated, and marginalized by the system (35). Instead, as previously reported (23), the participants in this study adopted a stance of cultural humility whereby they engaged continually "in self-reflection and self-critique as lifelong learners and reflective practitioners" (36, p119) and, via these processes, sought to redress the power imbalances that might otherwise exist in the professional–patient relationship. As a result of the cultural humility expressed by participants, this study has serendipitously captured cultural similarities and convergences rather than differences and divergences in the repertoire of strategies that nurses might use to meaningfully engage families whose cultural backgrounds and worldviews differ from their own and to foster quality nurse–family relationships.

In contrast to the findings of the study being reported here, some research has suggested that the professional–family relationship in EOL care contexts has not always been satisfactory, with families reporting high rates of not having their needs met—such as for information, emotional support, and to be treated with respect (37). This, in turn, has left some families feeling unsupported, abandoned, and, because of "not being properly informed," in a state of disequilibrium about what to expect (32). Studies have also shown that when families are not involved, there tends to be a "lack of understanding of others' perspectives, responsibilities, and roles"; relationships lack trust and certainty and ultimately become unproductive (38, p362).

The quality of nurse–patient–family relationships in acute care contexts has likewise been found to not always be satisfactory. For example, in a small Canadian grounded theoretical study, family members reported feeling as though they had "fallen through the cracks," which they characterized in terms of there being a "general lack of interaction between nurses and themselves" (14, p42). A key finding of this Canadian study was that nurses "expected" patients and families to ask questions. If questions were not asked, either by patients or their families, this was interpreted by the

nurses as an "unwillingness to engage" (14, p42). Significantly, patients and families whose first language was not English were particularly vulnerable to "falling through the cracks" and were left feeling ignored and that the nurses were "incompetent" (14, p42). There is scope to suggest that if nurses use the strategies identified by this study, the risk, incidence, and negative impact of NESB patients and their families "falling through the cracks" could be reduced.

Strengths and Limitations

A key strength of the component of the study reported here is the contribution it makes to a deeper understanding of the "right attitude" (the will to engage) nurses must have and the strategies nurses can use to meaningfully engage with families of older ethnic minority NESB patients hospitalized for EOL care. A limitation of the component of the study reported here is that it has had as its focus the views and accounts only of nurses involved in the EOL care of older NESB immigrant patients and their families. Future comparative studies investigating the views of the families of older NESB immigrant patients themselves would help validate the findings made and conclusions drawn and expand the knowledge base required to enable meaningful engagement of this population in EOL care contexts.

Conclusion

Nurses, who are at the forefront of caring for patients at the end of life, can make a profound difference in how patients and their families experience the dying process and the ultimate moment of death that will inevitably follow. The findings of this study highlight the essential role that nurses can be expected to play, as well as the strategies they can use to engage families of older NESB immigrant patients hospitalized for EOL care. They also serve to highlight that knowledge and skill alone are not sufficient for establishing, building, and sustaining quality nurse–family relationships with NESB families. A more fundamental prerequisite to the establishment and development of quality nurse–family relationships with NESB people is the "right attitude" apropos the will to engage. However, further work is required on establishing a clearer conceptualization of the will to engage, how it might be taught and fostered in culturally informed and nuanced ways, and how it might be operationalized both in policy and practice. Once this work is done, there is scope to suggest that benefits will accrue not only to older NESB immigrant patients and their families but also to all people across the lifespan in health-care contexts across the system.

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