ORIGINAL RESEARCH

Home care nurses’ decisions about the need for and amount of service at the end of life

Kelli I. Stajduhar, Laura Funk, Della Roberts, Barbara McLeod, Denise Cloutier-Fisher, Carolyn Wilkinson & Mary Ellen Purkis

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Abstract

Aims. We explore home care nurse decision-making about the need for and amount of service by clients and families at the end of life. We identify factors nurses refer to when describing these decisions, situated within contextual features of nursing practice.

Background. Home care nurses are often responsible for decisions which have an impact on the access of clients and families to services at the end of life. Understanding how these decisions are made, factors that are considered, and contextual influences is critical for improving access and enhancing care.

Methods. Qualitative data were collected between 2006 and 2008 from two samples of home care nurses: the first group (n = 29) recorded narrative descriptions of decisions made during visits to families. The second group (n = 27) completed in-person interviews focusing on access to care and their interactions with clients and families. Data were analysed with thematic coding and constant comparison.

Findings. Participants described assessing client and family needs and capacity. These assessments, at times integrated with considerations about relationships with clients and families, inform predictive judgements about future visits; these judgements are integrated with workload and home health resource considerations. In describing decisions, participants referred to concepts such as expertise, practice ideals and approaches to care.

Conclusion. Findings highlight the role of considerations of family caregiver capacity, the influence of relationships and the importance of the context of practice, as part of a complete understanding of the complexity of access to care at the end of life.

Keywords: access to care, decision-making, end of life care, home care, home care nurses, palliative care
Introduction

Few issues epitomize Western healthcare reform more than the move from hospital-based to home-based care. In developed countries, demographic shifts, scientific advancements and burgeoning costs have contributed to home care sector growth. Palliative care is a case in point: with population aging and increasing terminal diagnoses, many government policies promote community-based care of the terminally ill (Brazil et al. 2002). Both a family caregiver and home care nursing services are needed to effectively support home death, yet access to the latter can be problematic (Stajduhar 2003, Quality End-of-Life Care Coalition of Canada 2008), and in Canada, has been described as ‘the luck of the draw’ (Senate of Canada 2000).

Home care nurses (HCNs) are often responsible for decisions about home care services received by clients and families. Yet we know little about how HCNs make these decisions, what they consider, and broader contextual influences (e.g. organizational, political, economic). Understanding decision-making is critical for improving access and enhancing home-based palliative care. In this study, we explore HCNs’ accounts of decisions about the need for and amount of home nursing service for clients and families at the end of life, and identify factors they refer to when describing these decisions, situated within contextual features of palliative nursing practice.

Background

The large body of research and theory on clinical decision-making tends not to address access decisions, focusing more on decisions about patient condition and treatment. There is little research addressing home care decision-making, particularly palliative care. Broader research on case management decision-making, clinical decisions, and home care access and utilization, however, identifies potential influences on access decisions that may have relevance for clients and families receiving palliative services.


Other researchers have identified underutilization and/or a lack of timely referrals in minority ethnic communities (Ahmed et al. 2004) and lower socio-economic groups (Grande et al. 1998). Findings about client gender and age are less clear. Some research links greater access with being female (Grande et al. 1998, Payne et al. 1998) and older (Payne et al. 1998, Bowles et al. 2002); other research associates it with being male (Bowles et al. 2002) and younger (Grande et al. 1998, Ahmed et al. 2004). The presence of a family caregiver is also important (Alcock et al. 1998, 2002, Bowles et al. 2003), and tends to be associated with reduced service; when caregivers ‘burn out’, this may facilitate client access to specialist services (Bestall et al. 2004). Two studies also suggest when clients have terminal diagnoses, family caregivers have greater access (Grande et al. 1998, Ward-Griffin & McKeever 2000).

Home care nurse characteristics may influence decision-making (Tanner 2006): their ability to recognize cues and interpret situations may be influenced by previous knowledge, experience, education, cognitive strategies, care philosophies and role perceptions (Lauri & Salantera 1995, Bryans & McIntosh 1996, Alcock et al. 1998, Hallett et al. 2000, O’Brien-Pallas et al. 2001, Hendry & Walker 2004, Kihlgren et al. 2006). For example, case managers with personal family care experience may be more sympathetic to caregiver difficulties (i.e. providing more access: Fraser & Strang 2004). In another example, lower formal training was suggested as a barrier to access (Bowles et al. 2003, Ahmed et al. 2004).

We found no literature explicitly examining connections between provider-client or provider-family caregiver relationships, and either decision-making or access. More general literature points to the potential influence of such relationships; how this occurs is less clear (Alcock et al. 1998, Corazzini 2000, Bucknall 2003). For instance, clinical nursing judgment is influenced by knowing and engaging with the patient (Cioffi 2000, Tanner 2006).

Healthcare system features and cost constraints can influence decisions and access to care, through shortages in staff, beds, supplies and equipment (Alcock et al. 1998, 2002, Bestall et al. 2004), and related time pressures and competing demands. High caseloads and/or cost constraints have been linked to: shorter visits (Payne et al. 1998, O’Brien-Pallas et al. 2001); decision-making oriented to preventing future crises (Alcock et al. 2002); ‘rationing’ and priority-setting (Purkus 2001, Hendy & Walker 2004); ‘delegating as much care as possible to the family caregiver’ (Ward-Griffin & McKeever 2000, p. 95); and discomfort with providing ‘too much’ service too soon in palliative trajectories (Gallagher et al. 2002).

Decision-making tools and guidelines (e.g. for case management or referrals), and regulatory policies such as eligibility criteria (Alcock et al. 1998, 2002, Ahmed et al. 2004,
Kihlgren et al. 2006, Cabin 2007) can influence access decisions. There may be regional differences in interpreting such regulations (Alcock et al. 2002), and case managers may modify tools ‘to fit unique client situations’ (Fraser & Strang 2004, p. 5), paraphrase and supplement client responses to avoid ‘interrogating’ clients (Corazzini 2000), or ‘stretch the truth’ to increase services available to clients (Gallagher et al. 2002).

System and organizational features, together with changes in client types and needs (e.g. due to earlier hospital discharge), contribute to the ‘context of practice’ in which decisions are made, and indeed, decision outcomes (O’Neill 1997, Gallagher et al. 2002, Bucknall 2003, Tanner 2006, Lindeman 2009). For instance, decision-making differs between providers dealing with chronic vs. acute medical conditions (Watt 2000), long-term vs. short-term care (Lauri et al. 2001), and public health nursing vs. inpatient settings (Lauri & Salantera 1995). Such situational variability leads Fraser and Strang (2004) to suggest that case management rules and principles must be modifiable for particular contexts.

Gaps in knowledge about nursing decision-making persist; there is a need to examine decisions about access to services, and to understand such decisions in home care nursing, particularly palliative home care.

The study

Aim

Our aim was to explore HCNs’ decision-making about the need for and amount of service by clients and families at the end of life, through an analysis of their accounts of these decisions. HCNs’ decisions are conceptualized as contextual: embedded in broader contexts that directly and indirectly affect access decisions.

Design

A qualitative, multi-sample study was conducted in a Western Canadian regional health authority (May 2006–June 2008). To understand nurses’ decisions in the broader social contexts which shape them, we employed an ethnographic methodology. This approach explicated local theories (e.g. practice frameworks) that individuals use to explain their actions, in broader cultural contexts, and is well-suited to the discovery of explicit and situational cultural beliefs, knowledge and rules that guide behaviour (Hammersley & Atkinson 1995, Morse & Field 1995). Interviewing can be considered a form of participant observation (Hammersley & Atkinson 1995), and is consistent with our interest in nurses’ descriptions of their practice and decision-making (arguably not directly observable). In conjunction, we employed a modified ‘Think Aloud’ to record nurses’ narratives of the details of the decision-making process, including contextual and situational features (Fonteyn & Fisher 1995, Carnevale 1997, McLeod 2000). This technique has been used extensively in the study of nurses’ decision-making, is non-intrusive, grounded to participants’ immediate concerns, and minimizes time-lags, promoting recall (ibid).

Sample/participants

Participants were recruited in two separate phases. Sample size in both cases was determined based on assessments of data saturation (i.e. when only minimal levels of new information were evident in additional interviews).

Phase 1: Think Alouds

A purposive sample of 29 HCNs was recruited from all 15 home health offices in the health authority, through office posters, team meetings and an email to HCNs. Inclusion criteria were: (1) the participant would be a registered nurse employed by the health authority; (2) have practiced in home care for >1 year; and (3) work a minimum of 10 shifts per month.

Phase 2: Full Interviews

An additional sample of 27 HCNs was recruited using the same strategy and inclusion criteria as above (and a newsletter invitation to home health offices). Five HCNs who participated in the Think Alouds also volunteered to participate in this sample.

Data collection

Data were collected between May 2006 and June 2008.

Phase 1: Think Alouds

Twenty-nine HCNs completed brief, tape-recorded narrative descriptions of four or five decisions made during visits with families of clients with palliative conditions over a 2-week period. Recordings occurred shortly after visits. Approximately 1-week later, these HCNs participated in a follow up, in-person interview: they were asked to expand on and give further details of the context of their practice and considerations in their decisions. The goal of this study component was to document accounts of HCN decision-making in their everyday practice.

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Phase 2: Full Interviews
An additional sample of 27 HCNs (the ‘Interview’ group) completed in-person qualitative interviews designed to document their descriptions of interactions with family, and of elements of practice that influence a client/family’s access to care. Questions included, for example, ‘what affects family members’ ability to get help from home care nursing services?’ and ‘what is it like to work with clients and families in palliative home care?’ The goal was to document accounts and perceptions of nursing practice more broadly (e.g. beyond accounts of individual decisions).

Ethical considerations
Ethics committee approval was obtained from both the university and health authority. Written consent was obtained from all participants in the study, and participants were assured that their data would be considered confidential.

Data analysis
Concurrent with data collection, transcripts from both samples were read multiple times to identify recurring, converging and opposing themes and patterns (with acknowledgement and consideration to possible overlap between the Think Alouds and Interview data, given that five HCNs participated in both phases), key concepts, illustrative examples and possible linkages to theory. Summaries of individual interviews were created to facilitate a holistic, contextual understanding. Then, in each set of data, a thematic coding scheme was developed for the first 4–5 interviews, and then evaluated, revised and applied to remaining transcripts in NVivo 8.0 software. This work was guided by the orienting analytic questions, ‘what do participants identify as important considerations in their decisions about access to care for clients and families at the end of life?’ and ‘in what ways can decision-making be understood in the context of home care nursing practice?’ Data in each code or theme were then linked, compared, contrasted and further refined.

Rigour
Ethnography’s emphasis on the dialectical and iterative relationship between data collection and analysis facilitates verification and testing of inductively derived ideas (Agar 1997). Emerging findings were used to revise subsequent interview questions, to enhance descriptive and interpretive validity. Rigour was further enhanced through the triangulation of data collected from the two samples and with two methods (Interviews and Think Alouds), and by continually searching for exceptions and negative evidence (Hammersley & Atkinson 1995, Cresswell 1998).

Results

Sample characteristics
Demographic information on the two samples is given in Table 1. In brief, the Think Aloud group ranged in age from 40 to 63 years; 28 were female and one was male. HCNs in the Interview group ranged in age from 31 to 62 years; 26 were female and one was male. Years of home care nursing experience ranged from 1–31 in the Think Aloud sample, and 1–28 in the Interview sample.

Home care nurse decision-making
Home care nurses characterized decision-making in a complex practice environment involving various goals and considerations, including: (1) assessments of client and family needs and capacities; (2) relationships with clients and families; (3) workload and home care nursing resources; and (4) expertise, practice ideals and approaches to care. HCNs assess client and family needs and capacity; these assessments, at times integrated with relationship considerations, inform predictive judgements about the need for, amount and timing of home nursing visits; these are integrated with workload and home health resource considerations. In making these judgments, the HCN draws on her expertise, practice ideals and approaches to care.

The HCN’s assessment of client and family needs and capacities
Home care nurses described client and family characteristics that informed their assessments of needs and capacities, cited as a key influence on service access. Assessments involved multiple, repeated interactions over time; nurses re-evaluate depending on circumstances over time; they also predict future needs, to prevent crises. HCNs spoke about observing the ‘overall picture’ of the client/family and ‘what is going on’. As one described, ‘There’s a lot of things involved in seeing a palliative patient. It’s a very big picture. So when you go into a home for the first time, you look at what they know, where they’re at, what they want from the system and how they see you and what your role is and how it mixes with what their beliefs are and then you sort of start from there’.

Home care nurses spoke about assessing client needs and status. As one HCN noted: “Sometimes you just come out of
there and think, ‘Oh my goodness, where do we start?’ I mean some people are just in dire straights when you first look at them’. Specifically, HCNs assess physical and functional (e.g. illness trajectories, status stability/variability, complexity/multiple needs and symptoms), emotional, and cognitive needs. HCNs observed that increasing numbers of clients with terminal, non-cancer diagnoses create prognostication and decision-making challenges.

Home care nurses also described assessing family caregiver (FCG) needs, and particularly, FCG capacity (ability and willingness) to give care. Capacity is important both because the family is part of the unit of care, and, as one HCN noted, ‘when people can look after themselves then they can look after their loved one better’. FCG capacity is assessed based on information and perceptions about caregiver age, health, intellect/knowledge, emotional state, confidence, availability, experience, competing demands, living arrangements and language fluency. Concrete demonstrations of capacity include whether the FCG calls the HCN with concerns, follows the care plan, administers medications, gives input into care, and attends to their own needs. The following nurse described assessing caregiver burnout:

If they’re burning out and you think they’re trying to do too much themselves and you sort of pick up on that from experience. I think asking questions. Questions are the huge things, like, ‘How are you doing at night? Are you sleeping?’ I’m really aware of caregiver burnout. So I think it’s communication, just asking them and finding the cues and as you get more years of experience, you see more and more what people are doing, what they’re not doing and are they trying to do it themselves. I think every case is so different.

Lastly, HCNs assess aspects of capacity and need relevant to both the client and family, including individual personalities, values and beliefs, wishes and receptivity to assistance, preparedness and acceptance of diagnosis, expectations of home care (often related to previous healthcare system experiences), and socio-economic circumstances. They also consider the physical environment, family dynamics and conflicts (e.g. potential abuse), and other resources (e.g. family, friends, community services, other professionals), in determinations of overall need and capacity.

Home care nurses spoke of drawing on personal intuition, experience and knowledge, and obtaining information through questions, casual conversation, observation, listening, ‘subtle cues’, reading charts, and communicating with other providers. Sometimes, HCNs schedule more time with the same family to collect assessment information.

Home care nurses were less descriptive in explicating how their assessments influence access decision-making. In general, high need and low capacity among clients and/or
families requires more support. However, needs and capacities are at times weighed differently (e.g. priorities against the needs of other clients; client needs balanced against FCG capacity, etc.).

The HCN’s relationship with the client and/or family

Relationships with clients and families were described with emphasis on two benefits for HCN practice: getting to ‘know’ the client and family and establishing trust. These aspects of relationships help in assessing need and capacity (as above), and help ensure smooth future interactions. For instance, a trusting FCG will call if help is needed, and accept nurses’ suggestions and decisions: ‘she started to phone me if there was a problem. If something was different or if she wanted something, she felt comfortable just calling the office’. Another HCN stated: ‘the next time you have a suggestion, they’re more likely to follow it. And they will be forthcoming’. Highlighting the overlap with assessments, another HCN notes that relationships helped her ‘know how it’s all going to go’.

Home care nurses described how relationships might influence access to services. First, relationships allow HCNs to gather information about needs and capacities (indirectly affecting her decisions). Second, to facilitate relationships and trust, some HCNs schedule relationship-building time. HCNs described how they protect, maintain or build relationships, and spoke of barriers to relationship-building (client referral timing; staff/information discontinuity; time/workload constraints; the need to address difficult palliative topics).

Relationships are instrumental for good practice and decision-making; however, some HCNs suggested they potentially negatively affect decision-making. In difficult relationships, HCNs described the need to manage personal negative reactions, to ensure access – for example:

If the nurse is able to sort of take a breath and not take it personally and be open, there is still the possibility for that connection. If, for whatever reason, the person is set off, whether it’s a racist comment that’s made… I mean there’s any number of things… where the nurse just kind of goes, ‘Oh, okay, you don’t want us’.

Additionally, in enjoyable relationships, HCNs described how staying ‘professional’ involves setting service boundaries, as in this excerpt:

…when you have made a connection with a client when it doesn’t seem that other people have. And to be objective, there should be recognition that this could be manipulation behaviour by the client or, this should be a red flag, that the client is identifying that there’s only one nurse that understands them. But when you’re caught up in

Several HCNs acknowledge that good relationships can facilitate access, albeit at the expense of HCN well-being and time, or the needs of other clients. As such, relationships and judgments about personal-professional boundaries may affect access in different ways.

The HCN’s workload and home care nursing resources

Home care nurses referred to constraints on access over which they had little control, such as delays in and/or lack of availability of related services such as hospice residence admissions, equipment/supplies and home support. When translating predictive judgments about the need for help into service decisions, HCNs consider available home care resources and their workload. HCNs indicated they generally work in an under resourced environment, and resources for clients with palliative diagnoses are strained by increases in clients with chronic conditions and high complexity and need in both groups. HCNs described resource barriers (staffing limitations and restrictions on service) and difficulties managing increasingly large workloads. Such challenges are exacerbated by other demands on HCN time – e.g. travel distances, parking difficulties, ‘learning curves’ for new computer software.

How does a heavy workload have an impact on HCN decision-making? Some HCNs prioritize the needs of some clients relative to others, or defer care for some clients/families. Others spoke of ‘making the time’ for high-need clients within existing workloads; balancing caseloads; visiting clients with less serious needs first in the day; or transferring visits to other nurses, if available. HCNs attempt to mitigate the effect of resource constraints on access to care, by anticipating and trying to prevent problems arising outside of regular service hours, or when staffing might be low. In some cases, they skip breaks or work overtime, or ‘go above and beyond’ to contribute unpaid or special work for clients.

The health authority’s system of assigning time for HCN visits is based on estimates of predicted time for each scheduled visit (although there are office and HCN differences in how time is estimated). Time estimates for future visits are often made by the HCN who last visited, or an office-based nurse. Where a HCN perceives a particular client requires more time than originally estimated, she might adjust the time, or hope her day ‘balances out’. Some nurses said that the 1 hour often assigned for palliative care visits is insufficient, resulting in heavy workloads and unaddressed needs: ‘How can you do a visit, drive, chart, make all the...
phone calls, in 1 hour? Some HCNs, particularly when they know the client/family well, may sense the need for and address more issues, thus requiring more time.

Home care nurses described how unpredictable needs arise at end of life, yet their ability to respond can be limited. One nurse noted, ‘‘you always have clients [charts] lined up on the desk and if ever it’s a pleasant day or somebody might have some ‘wiggle room’ or flexibility, the first thing that gets done is, ‘let’s squeeze some more clients on’’. Full-time nurses may have greater flexibility (working more consecutive days/in a consistent district). While there was an overall sense of lack of control over workload and available time, nurses generally expressed greater control over particular visit decisions (perhaps related to full-time status, or office variations in scheduling).

The HCN’s expertise, practice ideals and approach to care

Many judgments are involved in HCN decisions, ranging from what information to consider in assessing need and how to interpret it; whether relationship-building requires extra time; appropriate relationship boundaries; how to weigh different clients’ needs; and how to manage workload. There is substantial variability in how need, capacities, relationship considerations and resource considerations are balanced in decision-making. For instance, some nurses, prioritizing boundaries, sought to avoid family dependence on individual nurses, others prioritized reducing family anxiety, arguing that a smaller nursing team facilitates family trust.

Home care nurses invoked reference to common practice ideals (such as ‘knowing the family’), perceptions of their role (e.g. expertise), and approaches to care (such as ‘empowerment’ or ‘caution’) as justification for decisions. These included beliefs about HCN involvement in family decision-making (e.g. referring to ‘boundaries’), and self-management and client/family responsibility (e.g. referring to ‘empowerment’). HCNs also commonly cited greater vulnerability (emotional needs and burden) in families facing terminal illness. Again, there is variability. Some HCNs defined ‘caution’ in decision-making as planning more visits to ensure future client needs are met; others defined it as holding back on visits (or overnight support) even in crisis, because it may be difficult to ‘pull back’ when the crisis resolves.

Some practice ideals stem from organizational culture and tradition (learned through education/experience). Offices may have ‘unofficial’ expectations about visits, and office tradition may be reinforced through pressures between HCNs: e.g. some nurses said that other nurses question their time estimates. Again, there is variability: one HCN identified her office tradition, but moved away from it, justifying her decision thus:

For us, it’s just the way it’s done. We tend to see people weekly. With this one particular client, I thought, ‘This is getting ridiculous’. We don’t need to see her weekly. She’s now down to once a month with a telephone call in between, and [the client is] quite annoyed with us. But it’s a judgment call and, I’m not taking [the client’s annoyance] personally... The way I’m looking at things, there’s other people with greater needs that could better utilizing the nursing.

Lastly, for some HCNs, assumptions can influence judgments, often unconsciously. For example, one HCN described how she believed a son caring for his father would not attend to his father’s needs because he was male, and the two ‘lived more of a bachelor kind of situation’. This example highlights connections between individual judgements and societal contexts – in this case, gendered norms influence the assessment of FCG capacity.

Discussion

Study limitations

This study was undertaken in one Western Canadian health authority, inherently influenced by local history and organizational culture. Findings may not be fully representative of home care nursing practice across Canada or in other countries; this underlines the importance of developing our understanding of contextual influences on decision-making and access; comparative research is also needed. We also acknowledge the limitations of interview data: participants can have difficulty articulating logical rationale for decisions (Luker & Kenrick 1992, Sims et al. 1992), and interviewing them after making decisions may generate accounts and justifications of decisions taken, as opposed to identifying causal predictors (Gubrium & Holstein 2000). Egan et al. (2009) recommend in-depth case study methods; an institutional ethnographic design could also give new insights.

Discussion of findings

Despite these limitations, this study is the first we know of to comprehensively identify how HCN relationships with clients/FCGs have implications for access decisions. In addition, findings confirm research on nursing and case management decision-making about the importance of assessments of client characteristics, while further illustrating how FCG needs and capacities are also considered. The UK End of Life Care Strategy (Department of Health 2008), for example,
What is already known about this topic
- General research on case management, clinical decision-making and home care access and utilization suggests client characteristics affect nursing decisions and access to care.
- General research on case management, clinical decision-making and home care access and utilization suggests nurses’ characteristics and education affect nursing decisions and access to care.
- General research on case management, clinical decision-making and home care access and utilization suggests healthcare system features and cost constraints affect nursing decisions and access to care.

What this paper adds
- Findings confirm, in palliative home care, the importance of assessments of client need and capacity, while also identifying the importance of considerations of family caregivers.
- Findings highlight the implications of relationships between home care nurses and both clients and family caregivers, in terms of access to care and decision-making.
- Findings reaffirm the ways in which home care nurses’ decisions about visits are influenced by their context of practice, including large workloads and system constraints.

Implications for practice and/or policy
- Models of clinical decision-making should incorporate ‘relationships’ between home care nurses and both clients and family caregivers.
- Decision-making tools could promote appropriate access, but should be informed by an understanding of the complexity of decision-making, including the potential need for flexibility in response to situational variation.
- Access decisions should be conceptualized as part of clinical decision-making, and skills involved in these decisions as a home care nurse competency requiring structural and educational support.

acknowledges the distinct needs of FCGs and their entitlement to separate needs assessments.

Findings reaffirm the importance of constraints on access related to system finances, staff shortages and high case-loads (Payne et al. 1998, Ward-Griffin & McKeever 2000, O’Brien-Pallas et al. 2001, Alcock et al. 2002, Hendry & Walker 2004). HCNs perform case management work within their role, with concomitant dilemmas balancing client and system centred goals. HCNs in this study identified how this has an impact on their decision-making, and how they strive to ensure appropriate access – for some this involves ‘going above and beyond’ professional role expectations. Egan et al. (2009) and Cabin (2007) described how case managers and nurses seek to match information on client and family needs to available services and eligibility criteria, acting as ‘clinician-brokers’ and ‘mediators’.

In the context of fiscal constraints, there may be increased ‘rationing’ and priority-setting (Purkis 2001, Hendry & Walker 2004). HCNs raised these issues when talking, for example, about balancing the needs of some clients against others, a process reinforced by the generalist practice model in which they work. Combined with particular beliefs about the needs of clients and families facing palliative diagnoses, this could result in situations in which the needs of these families are prioritized above those of families without terminal diagnoses. Other research suggests that patients with terminal diagnoses may have greater access to services (Fortinsky & Madigan 1997, Payne et al. 1998, Ward-Griffin & McKeever 2000, O’Brien-Pallas et al. 2001, Allan et al. 2005). Individuals with advancing long-term illness, who generally have less easily defined end of life trajectories, are typically not defined as eligible for palliative home care, and may have reduced access to such services (Stuart 2003, Lynn 2005).

In addition, findings highlight organizational systems which, in this health authority, allocate standardized times in advance for HCN visits; these systems have the potential to exacerbate overall workload constraints and reduce schedule flexibility, with implications for access and decision-making, particularly as palliative care needs are often unpredictable.

In a palliative care context, this study confirms the importance of HCN beliefs and characteristics for decision-making (e.g. Bryans & McIntosh 1996, Alcock et al. 1998, Hallett et al. 2000, O’Brien-Pallas et al. 2001, Hendry & Walker 2004, Tanner 2006). However, what might appear to be ‘individual’ beliefs or approaches may have broader roots in organizational cultures, philosophies of nursing practice or socio-cultural norms.

Notably, participants rarely mentioned the use of decision-making tools and guidelines; one recently created tool had only been implemented in four offices by the time of this study. While such tools may facilitate appropriate access, their implementation should be accompanied by education for HCNs about their appropriate use. Further, careful
attention should be paid to what is included (and omitted) in such tools, and the extent of flexibility in their application.

In sum, HCNs described how they assess client and family needs and capacity (including client status and stability, and available resources); these assessments, alongside relationship considerations, inform judgements about the need for, amount and timing of home nursing visits; these judgements are integrated with considerations related to workload and existing resources.

More broadly, contextual factors are directly or indirectly implicated in access-related decisions. For instance, assessments about future needs tend to be more challenging for clients with terminal, non-cancer diagnoses; whether and how relationship considerations are integrated into visit decisions may be influenced by internalized practice ideals or socio-cultural assumptions; and how nurses balance their workloads may be influenced by scheduling traditions and systems. There is considerable reported variability between nurses and between situations in how various considerations are weighed. Individual nurse characteristics, and both the setting (e.g. the ambiguity or complexity of particular clients) and conditions (e.g. resources and organizational systems) of decision-making may contribute to such variability.

Conclusion

The acknowledgement and consideration of family caregivers within models and tools of home care decision-making varies between individual countries and healthcare systems, resulting in substantive differences in decision-making contexts (e.g. such as available services and professional roles). Despite these contextual, substantive variations, an overarching theoretical understanding of decision-making, which highlights the importance of context for decision-making, can help inform research and policy across healthcare systems.

This study enhances understanding of the factors contributing to home care decision-making at end-of-life. While aligning with some of the general literature on decision-making and access, findings highlight the role of FCG capacity in nursing assessments. Clinical decision models should also incorporate relationships between HCNs and FCGs, and care delivery structures and processes should support continuity, knowing and relationship building, while encouraging critical reflection on personal-professional boundaries. Further, decisions about access to services should be conceptualized as part of HCN clinical decision-making; skills involved in these decisions (which are often predictive) are an HCN competency requiring structural and educational support. Indeed, Lindeman (2009) recommends greater clarity about the training and education needs of those in client assessment roles.

We also need broader discussion about what constitutes ‘good’ decision-making in relation to access to palliative care, and which care delivery models support the case management role in palliative care practice. Finally, there is ongoing need to examine the context of practice, including the resource context, for a complete understanding of the complexity of home care nurse decision-making and access to care at the end of life.

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Conflict of interest

No conflict of interest has been declared by the authors.

Author contributions

KIS, DR, BM, DCF and MEP were responsible for the study conception and design. KIS, DR, BM, DCF, CW and MEP performed the data collection. KIS, LF, DR, BM, DCF and CW performed the data analysis. KIS and LF were responsible for the drafting of the manuscript. KIS, LF, DR, BM, DCF and MEP made critical revisions to the paper for important intellectual content. KIS, DR, BM and CW supervised the study.

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