Access to Care at the End of Life:

Encounters between home care nurses and family caregivers

**Final Report
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Table of Contents

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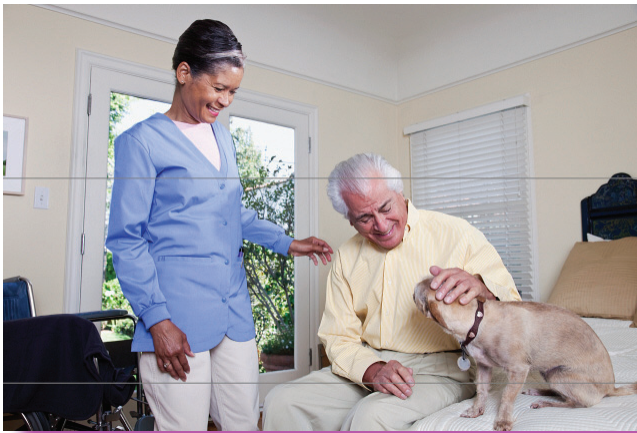**Department of Geography and Centre on Aging, University of Victoria**

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Executive Summary

Access to palliative care in the home continues to be problematic for many dying Canadians and their family caregivers (FCGs). Two of the most important components needed to effectively support dying at home are the availability of FCGs and access to home nursing care. Home care nurses (HCNs) have responsibility for making decisions about the need for and amount of home care nursing service. Despite this, we know little about how HCNs make these decisions. What do they take into account? How are these decisions shaped by broader contexts (e.g., organizational, social, economic)? Moreover, few studies have examined relationships between HCNs and families as mediators of access to care for dying clients and their family members. Such information is critical for improving access and enhancing the provision of home-based palliative care.

The **purpose of this study** was to gain a better understanding of how HCNs make decisions about the need for and amount of home care nursing services by clients and families at the end of life. In addition, we were interested in understanding the role of "relationships" in these decisions, and in access to care. Our ultimate aim is to develop guidelines to inform and support nurses' decision making about access, and to inform the development of health services and policies that improve access to palliative care.

Research Approach and Methods

This was a qualitative, ethnographic study. Data were collected in a variety of ways, between May 2006 and June 2008. There were two phases to the study:

In Phase 1, data were collected by 29 HCNs completing "Think Aloud" recordings after they visited a palliative client and family. These recordings involved having HCNs audio tape decisions that they had made during their home visits. The nurses were given a list of questions to guide their recording, and then about one week later, participated in a follow up interview to clarify points in the think aloud interview and address any unanswered questions. Additionally, nine "opinion leaders" and five team leaders knowledgeable about home health within the health authority were interviewed.

In Phase 2, 27 HCNs completed interviews focusing on what impacts a FCG's access to care, and 26 bereaved FCGs completed interviews about their experiences and relationships with home care nursing personnel.

Consistent with qualitative approaches, data were subjected to an interpretive thematic analysis.

Key Findings

Findings suggest that nurses consider various factors in their day to day decision-making about the need for and amount of home care service. While several factors were reported by nurses in this study there were *5 main considerations* that nurses talked about in their interviews. They were:

(1) *Relationships with Clients and Families:* Building relationships with clients and families is key to the HCNs' ability to make decisions. Relationships have two main benefits - the establishment of trust and getting to "know" the client and family. Engaging in relationship-building work is considered one of the most important activities that the HCN does to facilitate "good" decision making. When HCNs have time to build relationships, quality of care is enhanced, care delivery is more efficient, requests by clients and family for inappropriate levels of service are reduced, and nurses often report greater job satisfaction.

Our findings also suggest that relationships play a major role in influencing *access to care* at the end of life in several ways:

- Whether or not the HCN "knows" the client/family is key to assessing client/family need and capacity and, therefore, facilitates access to care;
- Whether or not trust is established in the relationship may affect whether or not the family will accept help and ask for it when needed, thereby influencing access to care;
- Home care nurses may book more time with the client/family or visits with them in order to build relationships;
- There may be a risk, in some interactions with clients and families, that the personal feelings of the HCN (e.g., feeling rebuffed, offended or uncomfortable), might negatively affect access to care;
- There may be a risk of the HCN becoming overly personally involved and providing too much service, thereby promoting dependency; Personal and professional boundaries of the HCN can sometimes get blurred and affect access to care.

(2) *Client and Family Characteristics (nurses' assessments):* Characteristics of the client and family (i.e., needs and capacity) influence HCN decision making. In making decisions, HCNs look at the 'overall picture' of the client/family drawing on their expertise, a combination of intuition and both professional and life experience, knowledge of end of life issues, and advice from other team members. In palliative care, client status is highly variable, requiring nurses to anticipate future needs. Increasing numbers of clients with non-cancer diagnoses create additional challenges for HCNs in prognostication and assessment. There is a high degree of subjectivity in assessments of need, as nurses have "different ways of looking" at things. Decision making tools can offer a common frame of reference in a highly complex environment such as palliative home care practice with multiple client and family variables as well as the individual nurses' variables.

(3) *Home Care Nursing Decisions - Approaches to Care:* The HCN's approach to care influences decision making. Depending on how a particular nurse interprets her role, for example (e.g., this is what I am willing to do; these are my personal and professional boundaries; this is what clients are entitled to, this is the most fiscally responsible way to allocate resources), how she applies resource considerations in her own decision-making varies. While some HCNs are concerned about boundaries and the possibility of promoting over-dependence, other HCNs contend that the family who know the nurse is available and responsive will have less client/

family anxiety, and more trust. Office tradition around appropriateness of visiting times seems, in part, to influence some HCNs decision making.

(4) *Home Care Nursing Decisions - Frequency of Visits:* HCNs make predictive decisions in an exceptionally complex, changing and often unpredictable clinical practice environment. Consequently, HCNs balance their work by both "planning ahead" and "taking it one day at a time" to account for the inherent flexibility needed as client/family conditions change. HCNs' visits are either planned (scheduled) or unplanned (unexpected). Unplanned visits typically occur because of client deterioration. HCNs consider stability in determining frequency of visiting and timing to prevent and/or avert a crisis in the home as well as meet the client/ family goal(s). HCNs emphasize that it is important to continue visiting stable clients, even if it is just once a month. Client/family status may change and the HCN is more likely to catch the signs at a visit. Typically, a stable client means fewer home care visits. On the other hand, a sudden client change or a client that is dying usually means a daily HCN visit. Home care nurses contend that averting crises in the home reduces costs to the health care system by preventing more costly services such as access through hospital emergency rooms and consequent hospitalization.

(5) *The Resource Context and Decision-Making - Workload and "Wiggle Room":* Resource considerations, including perceptions of the availability and appropriate use of resources, are part of the realities of nursing practice, and influence HCN decisions. Resources for palliative clients are strained by increases in non-palliative clients into the system and the level of complexity and need of both palliative and non-palliative clients. HCNs described numerous barriers within the system and the difficulties they face in managing their workload. They make decisions in the context of a workload that most of them describe as too large and increasing, with little "wiggle room." There is wide variation in how the "point" system of time planning is used between offices, and how points are assigned. Some (but not all) HCNs feel that with the point system, flexible time or 'wiggle room' in a nurse's day is limited, as is their ability to respond to unexpected requests or visits that require more than expected time. HCNs use various strategies to manage their workload. For example, HCNs prioritize client/family needs, anticipate and prepare for when staffing may be low, skip breaks or work overtime, and go "above and beyond" to contribute unpaid work for clients and families.

Recommendations

The 20 recommendations contained in this report call attention to the importance of (a) relationship building, (b) HCN decision making, and the (c) organizational context of home care nursing practice in palliative care. Recommendations arise from the research team's interpretation of the data and include those elements that study participants suggested are needed to enhance access to and quality of care at the end of life. Home care nurses and health authority decision makers also participated in three discussion groups and were asked to comment on the implications of the findings and assist with generating policy and practice recommendations.

Relationship Building Recommendations

The importance of relationship building was a central finding of this study. Such relationships are crucial for supporting effective HCN decision-making. Building relationships takes time, sometimes over several visits. The first visit with new clients and families in palliative care is often the most important one for setting the foundation for a 'good' relationship. Several factors hinder HCNs' ability to build relationships including the completion of numerous intake documents that can 'drive the visit,' becoming the focus of nursing practice rather than the client/family. Additionally, bereavement care is an important part of 'closing' relationships with FCGs (and preventing nurse burnout), but is often perceived as a luxury in a climate of fiscal restraint and full caseloads.

Relationship building recommendations include:

1. Undertake an analysis of palliative home care processes, practices and policies using a 'relationship lens'.
2. Acknowledge and define relationship building as a core competency in palliative home care nursing practice, and define strategies to support the development of this competency.
3. Establish a standard of practice for HCN palliative visiting that promotes relationship building, including expectations for the initial visit (e.g., ensuring adequate time for initial visits, considering continuity of nurses in the admission phase).
4. Adopt a streamlined and flexible approach to the admission documentation process to allow forms to be completed over the first few visits. Such an approach would promote and give more time to relationship building and enhance flexibility of admission visits.
5. Develop a standard of practice for home care nursing bereavement care, delineating the role of the home care nurse and the expected outcomes of bereavement care.

Decision-Making Recommendations

Access decisions are a key aspect of clinical decision making in home care practice, but are rarely acknowledged as such. Substantial individual variation in decision-making processes also exists in this regard. Such variability leads to creative problem solving, but decision-making can be challenging without a common frame of reference. Study findings validate concepts contained in the *Home Care Nursing Frequency of Visiting Decision Making Tool* that was implemented in Fraser South in 2003, and suggest ways to refine and further develop the tool. Despite the potential for tools to be useful in making decisions about HCN visiting and scheduling, no tools were identified that support the processes used in home care offices to make HCN assignments or scheduling of nursing visits. Development of such tools should take into account the client/family 'story' and be balanced with resources available in individual home care offices. As well, documentation and communication (continuity of information) was identified as a key influence on HCNs' abilities to build and maintain relationships (and therefore make good decisions), particularly in the absence of staff continuity. Having access to client/family information contributes greatly to 'knowing' the client and family. Thorough, accurate, yet condensed documentation is required to increase efficiencies, particularly for home care offices that have fewer resources (e.g., in rural settings). Finally, making decisions about eligibility for palliative services was an area that HCNs said created considerable tension when there was a lack of clarity about when a

client should receive palliative service and at what level, such as for those clients with advancing non-malignant diseases. Study findings suggest that clients with chronic illness not designated as palliative have less access to home care nursing services than those who are as palliative. The needs of palliative home care clients tend to be prioritized above the needs of non-palliative clients because it is perceived that those who are palliative have greater needs.

Decision making recommendations include:

6. Acknowledge that access decisions are a key aspect of clinical decision making in home care, requiring a clear description of the skills and abilities involved in access decisions. Support is needed for the development of this competency with decision making tools, processes and education.

7. To strengthen access decision making, use the research findings to modify the *Decision making Tool for Home Care Nursing Visiting (2003);* Implement the revised 2003 decision making tool across home health offices and then evaluate its utility for informing clinical decision making about access.

8. Review and revise the process of determining the daily home care nursing assignment that both considers the effect on relationship building and includes consideration of the rationale the HCN uses to predict the date and time for the client's next visit.

9. Revise the documentation and communication systems, as needed, to support HCNs in their assessment and decision-making.

10. Utilize technological advancements (such as: mobile technology aids) to enable HCN to have the right information about palliative client at all contacts.

11. Acknowledge the tension that home care nurses are experiencing in relation to accessing palliative services for clients with advancing chronic illness.

12. Review the issues of chronic illness and the implications for home care service delivery criteria to address the palliative care needs of this population.

13. Refine policies outlining service eligibility criteria according to chronic illness trajectories including cancer, to support HCN access decision-making.

Organizational Context Recommendations

Continuity of care is a significant factor influencing relationship building and access decisions. The current model of generalist HCN practice makes continuity of care difficult to achieve. Participants identified that change in the current care delivery model is needed to support continuity. Relatedly, there was strong support for scheduling visits not just on the basis of efficiency and standard estimates (i.e., using the Home Care Point System), but also considering the nurses' knowledge of the client and family. The current Home Care Point System is operationalized differently across offices and concern was raised that it does not match current practice reality. Organizational structures, policies and practices are also needed to protect HCNs from potential burnout that can be associated with relationship building work, and with working in increasingly overwhelming, highly complex environments such as palliative home care. Finally, participants noted that dying at home may not be an achievable choice for some people in more rural and remote areas, where resources such as hospitals, access to HCNs and increased reliance upon palliative volunteers are part of a 'system' with fewer resources overall. HCNs expressed a deep sense of responsibility when a client's transitions cannot be addressed in the home and they must be admitted to hospital. Smaller geographic centres face particular challenges as well as notable gaps in access (fewer staff, longer distances, less home support available).

Organizational context recommendations include:

14. Review the structures and processes of the home care delivery system for palliative patients in relation to the ability to support continuity, knowing and relationship building.

15. Review the literature and current practice models in order to identify home health care delivery models that promote relationship building, continuity, and safe, ethical practice.

16. Consider how care delivery changes can be made to enhance care for palliative clients and families.
17. Conduct a literature review of community-based "work-load" scheduling systems including the Fraser Health *Home Health Points System,* as it applies to the palliative home care population to see how current practices support HCN decision making. Such a review should address how current scheduling and the *Fraser Health Home Health Points System* include relationship building work.
18. Review nursing structures, policies, and practices to examine their implications for nurse burnout.
19. Provide opportunities to HCNs to openly discuss personal-professional boundaries and the HCN-client-family relationship.
20. Retain levels of flexibility in health authority wide policies to take into account the resource environment between different home care offices and geographic areas.

Access to at-home care continues to be a major problem for dying Canadians and their FCGs. The role of HCNs as gatekeepers of access to care will become increasingly critical as resources are stretched in home care. HCNs occupy a pivotal position within the health care system and are uniquely situated at the front lines with intimate clinical knowledge of the palliative home care situation. They play a key role in decisions related to service allocation and in influencing access to home nursing care. Understanding the factors that HCNs take into account when making decisions and examining their encounters with FCGs in palliative care has helped to generate knowledge concerning the complexities of access, the factors shaping HCNs' decisions and inform the development of health services, policies, and decision making guidelines aimed at improving access to care for patients and FCGs in palliative care.

Access to Care at the End of Life: Encounters between home care nurses and family caregivers

Background and Research Objectives

Access to palliative care in the home continues to be problematic for many dying Canadians and their family caregivers (FCGs). Two of the most important components needed to effectively support dying at home are the availability of FCGs and access to home nursing care. Home care nurses (HCNs) have responsibility for making decisions about the need for and amount of home care nursing service. Despite this, we know little about how HCNs make these decisions. What do they take into account? How are these decisions shaped by broader contexts (e.g., organizational, social, economic)? Moreover, few studies have examined relationships between HCNs and families as mediators of access to care for dying clients and their family members. Such information is critical for improving access and enhancing the provision of home-based palliative care.

The **purpose of this study** was to gain a better understanding of how HCNs make decisions about the need for and amount of home care nursing services by clients and families at the end of life[1]. In addition, we were interested in understanding the role of "relationships" in these decisions, and in access to care. Our ultimate aim is to develop guidelines to inform and support nurses' decision making about access, and to inform the development of health services and policies that improve access to palliative care.

Research Approach and Methods

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in a follow up interview with a research assistant to clarify points in the think aloud interview and address any unanswered questions. In addition, nine "opinion leaders" knowledgeable about the home care system (and specifically about palliative home care nursing practice) at various levels in the

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[1] For the purposes of this report, we are defining "end of life" as clients and families who are admitted into the palliative program of Fraser Health home health services. "Palliative" refers to persons living with an advanced life threatening illness.

health authority were interviewed by phone. Five Team Leaders were also interviewed and completed a brief questionnaire.

In Phase 2, 27 HCNs completed interviews focusing on what impacts a family caregiver's access to care, and 26 bereaved FCGs completed interviews about their experiences and relationships with home care nursing personnel.

Full details of the sampling, data collection and analytic process are provided in Appendix B. Demographic characteristics of all participants are summarized in Appendix C.

Findings

In keeping with the purpose of this study, we present findings describing the factors that influence nurses' decision-making about the need for and amount of service at the end of life, and then focus on how "relationships" between HCNs and families shape decisions and access to care. While the initial focus of this study was on FCGs in particular, nurses themselves often talked about the FCG, client and other family members in their interviews, often interchangeably. Thus, while some distinctions are made, overall the data reflect HCNs' understanding of the 'family' as the unit of care.

Factors Influencing Nurses' Decision Making about the Need for and Amount of Service at the End of Life

Findings suggest that nurses consider various factors in their day to day decision-making about the need for and amount of home care service. While several factors were reported by nurses in this study (see footnote below)[2] there were 5 main considerations that nurses talked about in their interviews and that are reported in detail here. They were:

(1) Relationships with clients and families;
(2) Client and family characteristics (nurses' assessments);
(3) Home care nursing decisions: approaches to care
(4) Home care nursing decisions: frequency of visits
(5) The resource context and decision-making: workload and "wiggle room".

(1) Relationships with Clients and Families

A primary factor influencing nurses' decision making is their ability to establish a relationship with the client and FCG. Indeed, nurses spoke about this relationship as key to their ability to make decisions

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[2] Though this report emphasizes 5 main factors influencing HCN decision making, several other factors were mentioned, to lesser degrees, in the interviews. These included: client/family preferences - often negotiated by HCNs as they seek goals that are feasible and realistic given the capacity of the family and the system. In addition, visits can be made for a variety of particular reasons involved in the work of supporting palliative clients/families, such as symptom management, assessment and monitoring, educating and communicating with FCGs, building and protecting the relationship with the client/family, and providing emotional support. The priority given to various activities varies between clients, over time, between individual nurses and often, between individual offices. Personal safety is also a consideration, including, for instance, dangerous home environments/dangerous clients/families, remote areas, and dangerous driving conditions.

(this will be discussed in further detail in the second half of this report). According to HCNs, the relationships they build with clients and families have two main benefits: the establishment of trust and getting to "know" the client and family (and the client and family getting to 'know' the nurse). Home care nurses and FCGs also talked about how they build relationships, as well as issues that can influence the development of relationships.

Trust and knowing

Home care nurses emphasized the importance of their relationship-building work in enhancing their ability to assess clients/families, and promote client/family trust in HCN care. A foundation of trust and "knowing" the client/family ensure things will go smoothly for both the client/family and the HCN. According to HCNs, such a relationship helps clients/families feel supported, enhances the family's well-being (e.g., by reducing anxiety), and helps things go more smoothly in future interactions with the client/family, possibly ensuring a better outcome. For instance, HCNs feel confident that family members will call them if they need help; they will also be more likely to act on the nurses' suggestions and be satisfied with her work and decisions. Trust is closely related to the idea that the client/family 'knows' the nurse, in the sense of trusting that she is competent, will do what she can to respond to needs; and are also aware of her limitations. When a client and family 'knows' the nurse, they may also be less likely to request inappropriate service that goes beyond the expected nursing role.

Interviews with HCNs suggested that trust and knowing are interconnected concepts: trust can facilitate knowing, and knowing promotes trust. Good (trusting) relationships allow the HCN to "know" information about the client/family that will help her/him best provide care. Trust promotes the sharing of information (such as information about client status, FCG coping) by the client/family. When HCNs have more information, they can better meet client needs with the most efficient number of visits and best results as this HCN suggested:

> *Initially you need to be connected to the client. And when the client feels confident, that rolls over to the family. Then the family feel confident and connected and are able to tell you things and share things that are going to [help you to] make your decisions in the future [about] how to visit these people and how to care for these people.*

While good (trusting) relationships can affect knowing, knowing can facilitate building, maintaining and protecting relationships (trust) with families. Several nurses emphasized gaining knowledge in advance of approaching a family (e.g., from the charts), to establish a relationship:

… sometimes we're seeing clients that we haven't seen before. A lot of times when it's a palliative you'll ask around the office 'I've never seen this man, what's he like, what's his family like?', 'Is there anything I need to know about?' Sometimes it's something very little and just knowing that little thing when you walk in the house, you know the dog's name or you know that they have a dog or whatever, that already breaks the ice and then they think that this is a person that I can trust or, of course we'll always the review the chart so that when you say 'how's that fentanyl 150 going?' and so then they think 'I don't know this person but they know all about me' and so then it opens the rapport.

Several nurses also described how 'knowing' can protect relationships – most often, in the sentiment that clients/families do not want to answer "the same questions" repeatedly, and that the less they have to do so, the happier they will be. Knowing reduces the potential for frustration in this regard, as well as giving clients/families a sense of "feeling important" (and being seen and heard).

Building Relationships

Most HCNs interviewed talked about the importance of establishing relationships with the client and FCG. In doing so, they tended to emphasize their own role in relationships. One nurse noted that if she could not establish connection with a client/family: "I feel like I'm lacking imagination, I'm lacking scope, I'm lacking an ability to be able to get through to where she's at and understand where she's coming from and then be able to address her on her own terms rather than the great white nurse coming in." Family caregiver (FCG) participants also expressed that "not being known" is difficult. Time for interactions and talk is important, according to FCGs: one FCG described an HCN who "probably knew me better than any of them because we sat and chatted and talked."

HCNs described several ways they protect, maintain or build relationships with clients/families:

- Respecting client/family choices and perspectives, being non-judgemental.
- Demonstrating knowing; avoid asking "the same questions" of family.
- Socializing, having a break from being overly medical and task focused.
- Identifying similarity/common ground between themselves and the client/FCG.
- Sharing personal information.
- Using communication techniques such as empathy and listening.
- Adopting a comfortable and sensitive approach with the client/FCG; being sensitive when introducing 'difficult topics' (palliative topics, DNR); not rushing.
- Responding to the family's personal scheduling needs when planning visits.
- Being on time, following through, finding out answers.
- Having something to offer in the relationship: information, expertise, and resources.
- Avoid being overbearing/be flexible (sense of timing; respect personality differences; adapt one's approach to the family).

Issues influencing the development of relationships between HCNs and families

In addition to their own role in establishing "good" relationships, HCNs cited broader factors that influence their ability to build and maintain relationships, such as:

- Timing of referral to home care nursing/client stage of illness (affects the time available and nature of interactions);
- Continuity/being full time staff/keeping visits to just a few primary nurses;
- Documentation/charting/communication between nurses/continuity of information (e.g., palliative rounds, information from the Cancer Agencies, family doctors);
- HCN time/workload.

The available health services and how care is accessed can also influence relationships with clients and families – as such, the reality of service limitations requires careful negotiation[3]. HCNs spoke about the need to educate clients/families about the limits of service, in order to reduce conflict; where conflict does occur, HCNs negotiate with clients/families to protect both resources and relationships. When families request services that are not available (or perceived by the HCN as not needed), negotiations can involve suggesting a compromise (e.g., offering one service while holding off arranging for another); encouraging families to be more realistic/less idealistic; building trust; explaining system limitations; not raising expectations (e.g. put in fewer services to start, rather than remove them later); encouraging the active involvement of family members in client care. Given the limitations in available home support hours and home care nursing availability ultimately, HCNs sometimes have to help families to decide between home care with its service limitations, or hospice residence death.

Other influences on relationships include the complexity of symptom management (when there are difficulties in symptom management, this can frustrate the family); whether or not family members are present during visits; being in the home environment (generally seen as enhancing relationship); similarity (of culture, religions, etc); client/family expectations, and client/family knowledge and acceptance of palliative status. Supporting clients and families at home in the final phase of life means that HCNs must discuss difficult topics such as the timing of death and the "No CPR" order. The need to address these difficult topics is also an important influence on relationships with clients/families, as well as nurses' decision-making about visits.

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[3] Policies designed to facilitate access for some groups (such as the BC Palliative Benefits program for those deemed by their physicians to have a prognosis of less than six months) may have unintended effects on relationships. In the case of the BC Palliative Benefits Program, clients sometimes live beyond six months, in which case nurses have to decide whether the client should be kept on the palliative program, or discharged/transferred to Long Term Care (which they may feel pressured to do in order to conserve resources).

Lastly, a key influence on developing relationships is the willingness or receptivity of the client/family to accept help. HCNs not only spoke of clients/families that do not want to share personal information (are guarded/private), but of the family's receptivity to trusting the nurse, or accepting help at all (often equated with receptivity to the relationship). For these reasons, relationship-building, as described by HCNs, can be understood as a mutual, relational process where the HCN gets to know families/clients, and they get to know and trust her; the relationship hinges on whether both parties are ready to engage (a willingness to be known, by both parties and an open-ness to 'the relationship').

Likewise, FCGs emphasized their own or the client's role in making sure they were "known" and communicating medical and/or personal information to HCNs. One FCG, for instance, noted that he and his wife "were good at stating what our needs were or our wants." Another FCG suggested the HCN got to know her in part because "maybe I was more open to it than some people." Indeed, one FCG suggested she should have been 'less private' and communicated more information about the client's history to the HCN, and felt some responsibility in this regard: "I definitely don't blame them; I blame myself for not being able to convey all of the things."

(2) Client and Family Characteristics (Nurse's Assessments)

HCNs emphasized client and family characteristics (i.e., needs and capacity) as a key factor influencing their decision making, and their own role in assessing these characteristics was described as a key influence on access to care. In addition, when asked about "knowing" the client and family in the context of relationships, nurses most often referred to knowing information that will help them assess client/family characteristics. Assessments ideally involve multiple, repeated interactions over time with both clients and multiple family members; nurses re-evaluate depending on circumstances. Ultimately, assessments about need represent an important type of HCN decision that affects access.

When describing "knowing" the family, HCNs often spoke about looking at the 'overall picture' of the client/family. Gathering information involves a combination of: asking direct questions, casual conversation, observing interactions, noticing body language, listening, picking up 'subtle cues' and indirect communication (e.g., 'reading between the lines'), noticing the condition of the home environment, reading charts, and communicating with other providers and other nurses (e.g., Palliative Rounds). HCNs draw on expertise, a combination of intuition and both professional and life experience and knowledge of end of life issues. In the absence of adequate established hospice palliative care expertise, HCNs (particularly those new to the field) draw on the expertise of other team members, other professionals, or clinical resources. Notably, there was very little emphasis on the use of decision-making tools, although the Palliative Performance Scale (PPS) was noted as being helpful in this regard.

As well as the overall picture of "what is going on" to base their decision-making, HCNs seek specific and comprehensive information about and assess the following:

- Client status (physical, emotional functional, cognitive, illness trajectory/disease diagnosis, PPS, stability/status variability, complexity/multiple needs, symptoms and medical history)
- FCG capacity for caregiving: including FCG ability and willingness (age/physical/health, intellectual/knowledge, emotional status/anxiety/fear, confidence, availability, experience,

competing demands, living arrangements, language fluency). According to most HCNs, concrete demonstrations of capacity include whether the FCG calls the HCN with concerns, follows the care plan, administers medications, provides input into the client's care, and attends to their own needs.

- Factors related to both the client and family: their personalities/styles; values/beliefs; wishes and receptivity to assistance; preparedness (including acceptance of diagnosis); knowledge/ expectations of HCN services (often related to previous experiences within the health care system); socio-economic circumstances and physical environment; family dynamics and conflicts (e.g., potential abuse); family support systems (e.g., family, friends, community members and other providers available to help).

Client status is highly variable over time and from day to day, requiring nurses to anticipate future needs. Adding to the variability, increasing numbers of clients with non-cancer diagnoses create additional challenges for HCNs in prognostication and assessment. Not only are the client and family factors complex, the nurse who is making the decisions brings her own assumptions to the decision making. For some HCNs, assumptions play a role in assessing client/family characteristics, often subconsciously. For example, one HCN related a situation where she believed a male client being cared for by his son should be in institutional care because she assumed the son would not be attentive to his father's care because he was a man and the father and son "lived more of a bachelor kind of situation." Some HCNs, however, acknowledged that at times, assumptions prove wrong: "We've had clients that wanted to stay home and we thought initially, oh, there's no way that's going to work, and it has worked." HCNs also referred to the high degree of subjectivity in assessments of need, leaving it open to variation based on opinion or "different ways of looking"; as one nurse notes, "because they're not numbers and they're not….it's not math…they're people and we're people so it's different." Other HCNs stated that with the introduction of the PPS, this has improved: "everybody's got the same tools now to help them make the decision; whereas before you were kind of left on your own to do a lot of that." This comment reflects that decision making tools can offer a common frame of reference in a highly complex environment such as palliative home care practice with multiple client and family variables as well as the individual nurses' variables.

(3) Home Care Nursing Decisions: Approaches to Care

HCNs also have various **approaches to care** that influence their decisions. For instance, almost all nurses felt that their role and priorities with clients and family were different in palliative situations – there was, for instance, higher perceived emotional needs, and relationships were seen as deeper and more

intense. With other beliefs, however, there was a great deal of variability between nurses (which may explain a large amount of variation in decision-making). Beliefs and opinions about the acceptable amount of active involvement in the family's decision-making; and the appropriate amount of self-management and client/family responsibility, are examples. Approaches to care affect how considerations about needs and resources are applied in decision-making. For example, depending on how a particular nurse interprets her role (e.g., this is what I am willing to do; these are my personal and professional boundaries; this is what clients are entitled to, this is the most fiscally responsible way to allocate resources), how she applies resource considerations in her own decision-making might vary. While some nurses were concerned about boundaries and the possibility of promoting over-dependence, others argued that the family who know the nurse is available and responsive will have less client/family anxiety, and more trust. Several nurses defined "cautious decision-making", for example, as giving more service or planning more visits to be sure that the client's needs will be met; yet caution is defined elsewhere as holding back on offering visits/service (or for example, overnight support) even in times of crisis, because it may be difficult to pull back when the crisis resolves.

Ideas about appropriate approaches seem to be influenced in part by the office tradition with some home care offices having "unofficial" expectations. For instance, daily visits may be only considered appropriate when the PPS is 20-30%, or when pre-loading medications. In the following quote, one HCN identified her office tradition, but then made a plan that went against it:

> *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.*

Office tradition may be reinforced through pressures from other HCNs: for instance, some nurses felt that other nurses questioned their decisions about time they spend seeing patients.

(4) Home care nursing decisions: frequency of visits

Hospice Palliative Care services are situated within the broader organizational and social context of Home Health. End of life access decisions by HCNs are a nursing competency within Community Health (i.e., Home Health and Hospice Palliative Care). Home-based nursing practice and HCNs' decisions are pivotal

to providing care for clients and families at the end-of-life. HCNs make predictive nursing judgments and decisions about the need for and amount of service provided to patients and their families, in an exceptionally complex, changing and often unpredictable clinical practice. As one HCN stated: "Sometimes you just come out of there [the home] and think, 'Oh my goodness, where do we start?' I mean some people are just in dire straits when you first look at them." HCNs recognize that their predictions are not always correct. There seems to be a balance in their work of "planning ahead" and "taking it one day at a time". Client and family situations change so HCNs say that the best that they can do is plan for the client scenario that they think is likely to happen but to also be observant to the changing situation and change the careplan accordingly: "Sometimes problems creep up on people and if we don't monitor them [the client] on a regular basis, make them aware of the problems, then suddenly they are having the problem". Many factors influence HCNs access decisions such as the social context in which they are made, relationships with family caregivers and resource allocation.

In 2003, a decision making tool was developed to support HCN decision-making about when to visit next. Two Hospice Palliative Care Clinical Nurses Specialists led the development of this resource with expert HCNs using clinical practice wisdom since little evidence existed to guide the development of the *Frequency of Palliative Home Care Nursing Visits Tool.* Findings in this research study validate both the 2003 clinical practice wisdom used to develop the tool and provide a deeper understanding and grounding about what factors HCNs take into account when making decisions about the need for and amount to service at end-of-life.

Planned and unplanned visits

HCNs assess and reassess clients and family caregivers to decide the need for and the amount of home care nursing services at the end of life with the aim of facilitating access and equity of services to clients and family caregivers. As one HCN said: *"We constantly have to assess and reassess because nothing is static or staying in one place; it's a constant change".* HCNs *"know"* that the client and/or family caregiver status and situation can change at any time at end of life: "*There's so many things that happen and of course things don't happen in a linear way."*

HCNs make decisions within the Home Health social context and the individual Home Health office culture and logistics. HCNs' visits are either planned (scheduled) or unplanned (unexpected) and occur in the home and/or on the telephone from the time of referral to the Hospice Palliative Care Program until death and bereavement. Telephone calls allow HCNs to follow up between visits. It may be a scheduled telephone call that reveals the need for an actual visit or there may not be any scheduled contact that day but the client's needs have changed and the client or family have called the HCN. The reason for unplanned visits generally relate to the client's deterioration: increased pain, swallowing or breathing difficulties, infection, collapse and death.

HCNs predict (based on their clinical nursing judgment) when to schedule the next visit and how much time is required for that future visit as an outcome of their visit (both telephone and home visit). The HCNs' predictive decision is twofold: when to visit next and how much time is required in that next visit. The HCNs' primary goal to prevent and/or avert a crisis in the home at end-of-life guides the predictive nursing judgement and decision for a future planned visit and the decision to respond

to an unplanned visit as this HCN suggests: *"I'd rather be safe than sorry. I'd rather not deal with a crisis. I'd like to nip something in the bud".* HCNs balance their desire to avert a crisis with the client and family's wishes and copying style. Although the HCN may want to visit sooner, the HCN negotiates the next visit with the client and family realizing that the HCN may visit at a later date.

Stability, nursing judgment and decisions

HCNs make nursing judgements about the stability of the client and family situation. HCNs consider stability in determining frequency of visiting and timing to prevent and/or avert a crisis in the home as well as meet the client/family goal(s): *"We love the stable phase. It's so easy to predict".* Based on the HCNs' assessment and reassessment, HCNs determine whether or not the client and/or family situation is "stable" (i.e., very stable, stable, fairly stable, destabilized, unstable and crisis). Stability incorporates nursing anticipation. That is, the ability to predict the frequency of home care visits at the end of life. Inherent within the HCNs anticipatory decision-making is the HCNs ability to 'know': *"… What I've learned is you err on the side of caution and you keep them on [the program], because at that point they can crash really, really quickly".*

HCNs emphasize that it is important to continue visiting the stable clients as well, even if it is just once a month. Things may change and the HCN is more likely to catch the signs at a visit. Typically, a stable client means fewer home care visits. On the other hand, a sudden client change or a client that is dying usually means a daily HCN visit.

HCNs' decisions include strategies to promote stability and coping and prevent and/or avert a crisis in the home. Decisions are dynamic and constantly changing. HCNs respond to both planned and unplanned visits therefore, decision-making needs to be responsive and flexible. HCNs strategies to predict and respond to the need for and amount of service at the end of life are: anticipation; consultation and/or collaboration; clarification; facilitation; negotiation; delegation (family caregiver, community support worker); support; teaching; and evaluation. HCNs contend that averting crises in the home reduces costs to the health care system by preventing more costly services such as access through hospital emergency rooms and consequent hospitalization, as this HCN suggests: *"We [the HCNs] are sort of the eyes [of the health care system] in a way. And of course that old saying, 'prevention's worth a pound of cure, right? By nipping something in the bud you stop potentially more expensive things if that's the way that we're looking at it, which unfortunately you have to."*

Factors guiding predictive home care nurses' decisions

HCNs consider a number of factors about when to plan the next visit. Ultimately by considering all factors HCNs determine the risk to the client and family without a visit in the predictive nursing

judgement and decision. Factors considered in the overall client and family status/condition are: client performance using the palliative performance scale (PPS); client symptoms [needs and capacity]; family caregiver [needs, capacity and support]; stability; overall client/caregiver status/condition, goals of care, dying, death and bereavement.

Some factors such as relationship, knowing and the ability to anticipate what will happen between visits promote greater clarity about when to schedule a planned visit whereas other factors such as changes in the client condition and sudden crisis will mean the plan for visiting will need to be changed to meet the changing client and family needs. HCNs need capacity within their everyday workload to respond to these client and family changes to ensure access to end of life care: *"I feel the dilemma [of timing of decisions]. In other words, do I make that decision today or can I make it tomorrow. And it's really a judgment call and I feel you have to really be in tune with the family and sometimes you don't make, I mean sometimes you know, timing is everything".*

(5) The Resource Context and Decision-Making: Workload and "Wiggle Room"

Another factor influencing HCNs' decision making about the need for and amount of service at the end of life relates to the availability of resources. Interviews with opinion leaders suggested that it is the responsibility of the office nurse or team leader to consider resource issues such as staffing/workload/cost. However, our data indicated that HCNs themselves also consider the availability and flexibility of resources as well as their workload and the flexibility of their workload, in making decisions. Resource considerations, including perceptions of the availability and appropriate use of resources, are part of the realities of nursing practice, and influence HCN decisions.

While hospice palliative care services have gained profile and resources in recent years, participants indicated that more resources are still needed: one opinion leader cited that the health authority is currently 25% below the provincial mean in Home Health resources. Resources for palliative clients are strained by increases in non-palliative clients into the system (e.g., earlier release from acute care; those with life-limiting conditions) and the level of complexity and need of both palliative and non-palliative clients. HCNs described numerous barriers within the system (staffing limitations and restrictions on service), and the difficulties they face in managing their own workload. They make decisions in the context of a workload that most of them describe as too large and increasing, with little "wiggle room."

Keeping the office adequately staffed is a challenge, particularly on weekends and summer holidays. In addition, when clients/families do not have equipment and supplies in place, they require more HCN support; the time it takes to request and follow up with equipment is another demand. Such challenges are exacerbated by other demands on HCN time - for instance, the office layout, travel distances, and parking issues. Further, recent/new initiatives (e.g., a new wound care system; formal assessment tools such as InterRAI) require a steep learning curve, creating additional workload strain.

The "point" system[4] of time planning is accompanied by an expectation that nurses will work within

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[4]   Most of the Home Health offices in Fraser Health use the "point system". In the point system, one point represents 15 minutes of time. Nurses use the language of points rather than minutes to estimate how much time the work related to a particular

a standard number of points per day, based on an estimation of the amount of time a visit would take – however, there are wide differences between offices in how points are assigned. Where points do not match what the HCN perceives a particular client needs, she might adjust the points or leave them as is, with the hope that the overall assignment will balance out by the end of the day. The points system influences and inhibits HCNs' decision-making regarding access to care at end of life, including decisions about how much time is required at each visit. Some nurses felt that the four points (one hour) often assigned for regular palliative visits are not enough - workloads are heavy as a result and needs may be unaddressed: "How can you do a visit, drive, chart, make all the phone calls, in one hour?" Notably, some HCNs, particularly when they feel they know the client/family well, may sense and address more issues, thus requiring more time.

With the point system, flexible time or 'wiggle room' in a nurse's day is limited, as is their ability to respond to unexpected requests or visits that require more than expected time (although room may sometimes be gained from other visits that take less time). 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, however, relative to part-time and casual nurses, may have greater flexibility, by virtue of being on the job for more consecutive days and in a consistent district. Indeed, some HCNs suggested the point system does provide wiggle room; and while there was an overall sense of lack of control over workload size and time constraints, nurses generally expressed greater control in terms of their internal resource allocation (decisions about particular visits). This may be related not only to full versus part time status, but also to office variations in approaches to scheduling.

HCNs also referred to other constraints on their decision-making about the need for and amount of service, that are linked to resource limitations (as well as logistical limitations), including delays in and/or lack of availability of services such as: hospice residence beds (and delays in hospice residence admissions, lack of Home Health intake on the weekends); other professionals (doctors, especially, including physicians to do home visits); equipment/supplies (including hospital beds); services for food in the home; cleaning services; transportation; and the amount and type of home support. For instance, limitations to overnight home support can determine whether clients can remain at home, and home support regulations do not allow for housework, only personal care.

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client will take. Points are assigned to cover the time it takes to do the home or phone visit, follow up phone calls, or paperwork. In some offices, nurses assign points to cover travel time and in other offices they do not. Another area in which offices differ is whether or not they document actual points used, at the end of the day. Regular palliative visits are usually four points. Closer to end of life, the points may increase to six to eight points to allow time for tasks such as preloading syringes for subcutaneous injections. A palliative admission ranges from ten to twelve points, phone contact with the client is one to two points, and a joint visit with family physician or palliative consult physician is usually eight points.

Nursing decisions are made in the context of these resource limitations, and influence client/family access to services. HCNs described the following strategies they use to manage their workload, in order to visit clients as needed:

- HCNs prioritize the needs of clients relative to other clients; deferrals can result as HCNs "make the time" for some clients/families who may be identified as having greater needs (such as palliative clients) within their existing schedules/workload.
- HCNs attempt to balance their caseloads in terms of anticipated visit duration; may visit clients with less serious needs first and palliative clients later in the day.
- HCNs anticipate and prepare for when staffing may be low, e.g., by stocking up client supplies; anticipating and trying to prevent problems arising outside of regular service hours.
- HCNs might (if possible) offload specific visits to another nurse.
- HCNs might skip breaks or work overtime[5] particularly when unexpected client needs arise.
- Relatedly, HCNs may go "above and beyond" to contribute unpaid or special work for clients and families. This phenomenon will be discussed in a later section of this report.

Relationship Factors Influencing Access to Care at the End of Life

In the preceding section, we presented 5 main factors influencing nurses' decision making. One of the key factors relates to the development of relationships. In particular, findings suggest establishing trust and knowing with the client and FCG as key components in the decision making process. Our findings also suggest that these relationships play a major role in influencing access to care at the end of life. Relationships (knowing and/or trust) can influence decision-making and a client and family's access to home care services in several ways that will be outlined here.

> **"Knowing" the Client and Family: whether or not the HCN "knows" the client/ family is key to assessing client/family need and capacity.**

HCNs described assessments as a key feature in decisions about client/family's access to care – not only access to HCN services, but to home support services and outside resources. A good (trusting) relationship will promote the sharing of information by the family and client; in the absence of a good relationship, "they're not going to have that ease to open up to you to talk to you."

Knowing a family/client can help in making good decisions: "the more information you have, the more you can make a balanced decision." The nurses' knowledge of the client/family may justify more or less visits in the immediate or long-term, as well as influencing decisions about the type of visit, and amount of home support. When a nurse knows a client/family well, s/he may support them more

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[5] Whether overtime is allowed varies between offices; some nurses find this unfair.

effectively, potentially resulting in fewer visits. For instance, if the nurse feels that she knows a client/family well, "a little goes a long way," and she might sometimes make phone visits yet still remain confident in her ability to detect when a client is starting to decline. Alternatively, knowledge of the client/family may alert the nurse to various needs, and nurses may visit more frequently as a result. In this sense, "knowing" the client/family can affect HCN decisions about the amount and type of services, particularly HCN and home support.

> **Trust in the Relationship: Whether or not trust is established in the relationship may affect whether or not the family will accept help and ask for it when needed.**

Another way in which relationships can influence access to care occurs through trust, although the emphasis here is less on nurses' decisions and more on the decisions made by family. The idea that family members will decide to call if help is needed is one of the primary ways in which nurses described the *practical* value of trust. As one HCN stated: "…and then she (the FCG) 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." Because there are not enough resources for continual monitoring of all clients over time, many HCNs expressed concern if they thought that clients/families will not ask for needed help, or will refuse it when offered. Both HCNs and FCGs described various reasons that clients/families may do so, including:

- Desire for privacy/not wanting other people in the home;
- Denial of diagnosis/avoidance/not being ready (symbolic meaning of HCN/palliative);
- Overwhelmed/frustration with discontinuity/numbers of staff (not wanting to repeat information);
- Stoicism, trying to show they can cope (symbolic meaning of receiving help);
- Desire for independence, pride, control issues;
- Inability to recognize or articulate need for help (approach to coping, immediacy, lack of perceiving the need or lack of knowledge about what to ask for);
- Lack of trust in staff/providers; negative past experiences; perceived quality of care (note: FCGs tend not to use the word trust, but instead focus on evaluating whether help would be helpful or not, based on their past experiences).

Therefore, establishing trust in the relationship is key to enhancing access to care at the end of life. In the absence of trust, HCNs may decide to actively negotiate to promote access for the client/family, including:

- Explaining to FCGs that they need to look after themselves;
- Bringing along other service providers to a visit, to introduce them;
- Explaining how particular services might be beneficial in the future;
- Suggesting how services can be flexible to family needs;
- Exploring reasons for dissatisfaction with services and addressing them;
- Making the FCG feel like they have greater control in directing services;
- Asking families to "give it a try;"
- Asking clients to bring in services in order to help the FCG;
- Reassuring the FCG (doing a good job), but being persistent in securing additional visits.

However, HCNs are also keenly aware of the delicate balance involved in 'pushing' or being overly directive, particularly where this can jeopardize the relationship and thus future access. In addition, whether or not

trust is established in a relationship also means that clients/families may be less likely to push for inappropriate levels of service that the nurse tells them is not yet needed. That is, they trust the nurse's assessment and may be more likely to agree with her suggestions and decisions.

It is interesting to note that our data suggests that FCGs focus less on 'relationship[6]' in their accounts of interactions with HCNs (with the exception of the finding that some FCGs expressed a need to maintain a good relationship with their HCN, to protect client access). Overall, however, FCGs tend not to talk about 'relationships' with HCNs in an unprompted way. This may in many cases be because of a lack of sustained interaction with one HCN. In many interviews, the participant was not the family member most involved with the HCN; or could not recall who the HCN was, confusing her with home support, for example; or was not exposed to HCN interaction for a long enough or consistent enough period of time. In addition, instead of focusing on relationship (e.g. trusting or being known[7], in the same sense as in HCN accounts), FCGs focused on the following main aspects as important in their interactions:
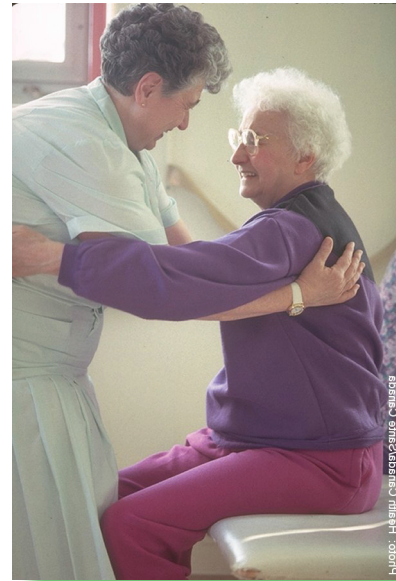
Caring for: It is important that the HCN seems concerned about the situation, checks in to see how things are going; has time for the client/family, stays as long as is needed, appears willing to help, responds to requests for help and follows through. Along with this practical support, FCGs preferred that the HCN provide clear guidance, telling them what to expect; they appreciated the knowledge and experience of the HCNs and being given honest and clear communication.

Caring about: FCGs appreciated 'warm,' 'caring' and 'friend or family-like' behaviours and communications described as compassionate, sensitive and empathetic (such as giving hugs). Behaviours that "go above and beyond" the normal nursing role were often interpreted as caring about, as was an unrushed manner and talking about social (non-task) topics. Further, most (with a few exceptions) appreciated the sharing of personal information by HCNs.

Comfort, calm and reassurance: FCGs appreciated HCNs that establish comfort and calm (e.g., through knowledge and experience, her manner/tone of voice, appropriate humour, an "atmosphere of acceptance," welcoming discussion and questions, not being overly official).

Respecting and acknowledging the FCG: While FCGs tended to focus on whether the client's needs were met, they also appreciated HCNs attentiveness to their own needs, helping them by listening, providing reassurance, activating other family support or dealing with family conflicts, and helping deal with difficult clients. FCGs appreciated when HCNs acknowledged and respected them, for instance supporting their decisions and valuing their input, complimenting them on care, and respecting certain protocols.

Relationship with client/respecting and acknowledging the client: FCGs appreciated when the HCN related well to the client, had a good rapport with them, and acknowledged and respected him or her (including them in conversations, preserving their dignity, treating them as a complete

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[6]   Similarly, in contrast to HCN accounts, FCGs did not emphasize "being known," and many did not feel personally known.

[7]   Indeed, a parallel analysis of the meaning of "being known" in the FCG interviews suggests that this concept, for FCGs, represents a feeling of being understood and cared about that emerges through positive interpretations of HCN behaviours.

person). One FCG spoke of the HCN's ability "to show in both her facial expressions and her body language ... that you may be sick but you're very much a person. You may be going to die but you're not yet.

> **Time to Establish Relationship: HCNs may book more time with the client/FCG or visits with them in order to build relationships (trust and knowing)**

Another way in which relationships can directly influence nurses' decisions and therefore access to care is that because of the value of trust and knowing, HCNs may spend time building relationships. Contact, particularly the initial assessment visit and subsequent in-person contact, is important. Nurses spoke about difficulties assessing the situation or picking up on changes over the phone, or that family may be less likely to open up. Once relationships are established, however, there was a sentiment that relationships can then be maintained with periodic visits and or phone calls, in addition to scheduled contacts.

The desire to maintain relationships can impact nurses' decisions around continuity (particularly of staff, but also of information). Much effort is put towards maintaining continuity for clients and families. Nurses may plan subsequent visits based on their own schedule, to make sure they can provide the next visit. While it will be necessary to introduce other nurses, they would prefer to do so gradually after they have established a solid relationship with the family. Nurses use documentation, verbal report, and/or voice mail when they are handing their clients over to a colleague. They may do joint visits with a nursing colleague or other team member to introduce them to the client and family. There was some sense that the full time nurse role lends itself better to continuity as the part time and casual nurses are not able to follow up as often. Because of the time and effort involved in getting to know, some HCNs felt that continuity of staff is most efficient: "given the importance of knowing the family, it may be a best use of staff resources to keep those staff who know the family, involved with that family, it will save them time because they know the situation."

HCNs were asked directly whether they would spend more time or schedule more visits to develop relationships: while not all HCNs agreed, those that did emphasized the practical benefits – e.g., enhances their ability to assess, and develops trust needed to provide good care in the future.

Opinion leaders who were able to observe nursing teams also noted variation in approaches to establishing relationship. Differences between nurses in this regard (which is in part about differences in role perceptions) can cause tension within the team:

> *I think that there are some nurses who spend a lot of time with families in relationship-building and I think we also have to respect that each nurse operates in a different way. There's no cookie cutter approach. And I think that the nurses who spend a bit more time are not looked upon favourably. But I think [those nurses] do a damn fine job.*

Other nurses described the benefits of maintaining continuity with a small team of nurses rather than just one nurse - constructed as providing the nurse with a break, protecting her from burnout; providing a fresh perspective and additional expertise; sharing responsibility between nurses; and preventing client

and family dependency on one nurse. The realities of the broader context are that logistical and staffing considerations may necessitate the sharing of clients between several nurses. In this context, nurses emphasized the need to build relationships and trust not only between individual nurses and clients/families, but also between the client/family and the whole nursing team or a subgroup of the team, or the health care system more broadly:

> *When I said consistency, it would not be one single nurse. It would be a whole team of nurses. We prepare all the clients that we visit for not only one nurse, because we do not want to build that single bond. Then the client is too dependent on one nurse and that will make caring for the client and the family very difficult…if they don't trust other nurses or other team members. So it will make caring for the clients and making plans very difficult.*

> **HCN Personal Feelings (negatively influencing access): There may be a risk, in some interactions with clients and families, that personal feelings (e.g., feeling rebuffed, offended, or uncomfortable), might negatively affect access.**

Some participants suggested that relationships can negatively influence access to care, when a nurse becomes overly personally involved with the family. In other words, HCNs may decide to visit less when they have negative experiences in relationships. To protect against this, HCNs attempt to put aside personal feelings and push through difficult interactions; they also rely on other team members. For instance, relationships can also affect nurses personally if the family is perceived to be unreceptive, closed, rude, or "cold and prickly" (particularly challenging when the nurse also perceives the client/family needs help). One HCN described what can happen if the HCN feels rebuffed and takes it personally:

> *If the nurse is able to sort of take a breath and not take it [feeling rebuffed] personally and be open, there is still the possibility for that connection. If, for whatever reason, the person [the nurse] 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."*

Another HCN was yelled at by a client's husband over the phone: "I was really quite shaken by it because you kind of feel like you're trying your best; you're trying to be respectful." This HCN was persistent, referring to how she would feel guilty if she had given up and not returned; this persistence succeeded: "we came to a strange understanding so that we could work together for her [the client]." Managing personal emotions thus helps protect against situations in which poor relationships might negatively influence access to care.

While several HCNs felt that negative interactions or negative feelings about client/families would not affect access, there was also a sense that it 'should *not* ' do so. For example, one nurse noted: "it shouldn't have made any difference, and it probably didn't." Nonetheless, other HCNs expressed that "relationships" (e.g., whether or not the HCN feels comfortable in interactions) can negatively affect access**:** "I see it just in how long say a nurse would even stay in a home." One HCN described unclean, smoky home environments: "you don't want to spend a lot of time in there." Another HCN suggested that "if someone is very difficult to deal with and the staff don't want to go there," this would affect visits (albeit

perhaps unintentionally), unless the client/family called for help or there is a set up, agreed upon time for visits. While another HCN did not feel that negative relationships would actually result in stopping care, she suggested that where clients/families were "nasty" to her, she may be less likely to go "out of her way" to be helpful (e.g., to dig deeper, be as creative) – she wondered about these difficult families: "would they get the whole heart and soul of that nurse that's going in? Probably not because there would be the need to protect themselves emotionally and psychologically, they've got that barrier up." Further, where aggressive clients or families are assessed as potentially threatening safety, HCNs may restrict access.

With the exception of safety concerns, difficulties between HCNs and clients/families are often addressed by bringing in other team members. This can buffer the potentially negative effect of rocky relationships on access. One HCN stated that difficult relationships with families do affect access ("I think that's human nature"), but adds that the "buffing zone" is being able to pass the case to another HCN who may be better able to make a connection or not find a family difficult to work with.

FCG participants perceived a need to maintain good relationships with HCNs and health care professionals. Some FCGs were concerned that being too active or assertive in requesting service may damage their relationship with HCN(s), and thus access to care. One FCG, for instance, perceived that her assertive behaviour negatively affected her "relationship" with the HCN department, and that this negatively affected access: "just to put it bluntly, I feel like I pissed them off." Another FCG perceived that HCNs resented her active attempts to seek her own answers: "they would say to me things like, 'Aren't you creative.' And it wasn't meant nice" ; "it was like 'Huh, she doesn't listen to us. She doesn't want to listen to us.' Which wasn't true." Another FCG emphasized how she tried to protect and maintain a good relationship with the home care nursing staff, because she believed that 'not rocking the boat' would protect the client:

> *I did not want to have any kind of problem, with her (the HCN) being upset at us - even though she's a professional person, I want my mom to be really well looked after. And people do this all the time, right, with…the professional health care people, right? We want the best care and we think if we annoy you you're not going to give our loved one…. even if we're wrong, we can't help thinking that way, right?*

In this sense, FCGs were acutely aware of how relationships can affect access to care.

> **HCN Personal Feelings (Going 'Above and beyond'): There may be a risk of becoming overly personally involved and providing too much service, promoting dependency and/or being manipulated.**

According to some HCNs, close relationships between nurses and clients/families can influence nurses' decision-making and access to care. Thus, some of the HCNs try to 'maintain boundaries' to ensure against inappropriate (e.g. excessive or unwarranted) access. Where the boundary is set varies between individual nurses, and is an important part of HCN decisions about service. As mentioned earlier, knowing a family/client can help in making good decisions. However, there was also a sense of a limit at which 'knowing' the client/family raises the possibility for biased decisions, for instance when the HCN 'knows' too much: "the things you know most intimately have a little more vested interest and a

little more concern that things get done a certain way because you're more aware of how it could affect the person." Several nurses suggested that knowing a family too well, and/or having a 'good connection' or relationship, can blind nurses to the potential for manipulation and blur boundaries:

…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 a 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 the thick of things in caring for someone, the priority becomes providing the care.

Through managing their emotions and boundaries within the relationship, HCNs attempt to avoid becoming overly personally involved. Relatedly, nurses expressed that the relationship should not promote 'dependence' on the nurse, and that the nurse should not depart from her normal role, such as giving out her cell phone number, contacting or visiting on her off hours or more than needed, visiting the family in Hospice, or keeping in touch with the family after death:

"[the family] want to give you gifts or they want to do different things like that and lots of nurses get caught in that and then, "Oh, I'll give you a little phone number after work. Just call me if anything comes up." So then you get into all kinds of layering of these boundaries where once you get your foot across that line then you're going. You're sliding down the slope."

Another nurse suggested that if a nurse is personally involved, the family will demand too much, and the nurse will provide it (thus losing her objectivity, providing more service/ visits than appropriate, or blurring her life-work boundaries by contributing personal time). Being overly involved was often described as "getting to be the family yourself." These limits are about the boundaries of service and expected roles, which are subject to significant variations. In this sense, the limits of 'relationship' are determined in part by the resource/ service limits of home care nursing, and in part by HCN opinions about appropriate roles.

Despite the risks, however, many HCNs described how they go "above and beyond" to contribute unpaid or special work for some clients and families. This includes personal decisions to work overtime, through their lunch breaks, and otherwise contribute unpaid hours or make special efforts beyond that which is a required part of their work, such as visiting clients in hospice or attending funerals. In some cases, these decisions are motivated by their palliative philosophies. In other cases, it stems from the desire to build relationships and/or a desire to help that stems from good relationships. Relationships may also, for instance, create feelings of responsibility for clients/families.

One HCN described how she visits palliative clients in hospice/hospital: "I've looked after them for like, six months or two weeks. I think it's pretty cold to leave them." She added: "because you have a

connection with people, especially when you're going every day; and it's not a case of going over boundaries with them because you build up this rapport with them. You build up a relationship with them; they trust you and they know that you're trying to help them." The quality of relationships may also be important, as with the following HCN participant:

> *P: I told one client recently because I've got a good relationship with him and a lot of people don't like going to his house. It smells like smoke and he's crude and he's crusty and you know his mother rolls her eyes, but I can see a bit of fear there, I can see as he's deteriorating that he's not quite as in control and I told him recently, I said, "When you go to Hospice I'll come and see you there." I said, "I think you're going to need some visitors."*
> *I.: Yeah and again that's kind of on your own.*
> *P.: Yeah, absolutely. I wouldn't expect to be paid for it.*

When discussing either being personally involved or allowing personal feelings to influence relationships and thus, access to care, HCNs tended to describe relationships (trust and/or knowing) as unprofessional or overly subjective, and needing to be controlled to promote objectivity and professionalism. There was an emphasis on avoiding letting "personal" emotions, views or beliefs affect judgement and treatment of a client/family, and the need for maintaining boundaries, to limit relationships.[8]

Summary

In sum, nurses' make predictive decisions about the need for and amount of service for clients and families receiving palliative home care services are made within a tremendously complex, changing and often unpredictable clinical practice environment. HCN decisions are the result of weighing multiple considerations including assessments of client and family characteristics (particularly needs and capacities) that are variable and changing, the influence of their relationships with clients and families (the importance of and interconnection between trust and knowing); workload and resource considerations; and perceptions of appropriate approaches. Common strategies were described, yet the particular ways in which each nurse made these decisions varied greatly. The factors that HCN identify as important considerations in their decisions provide direction for the development of practice supports for decision making. As one nurse described: "so that everybody's got the same tools to help them make the decision; whereas before you were kind of left on your own."

The particular ways in which they make these decisions can vary between and among nurses. One particular interest in this study was in examining the various ways, that 'relationships' are part of nurse's decision-making about the need for and amount of service for families at the end of life. The data suggested five primary ways in which relationships affect a client/family's access to care, the following four of which illustrate ways in which relationships operate in nurse's decision-making:

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[8] HCNs also attempt to manage the emotional impact of their work on them personally, in order to cope. For instance, HCNs face challenges dealing with issues of closure and grieving when clients die or for other reasons, their relationships are abruptly closed. Maintaining boundaries between personal and private lives, for some HCNs, means a limit on 'personal' relationships, most notably in terms of sharing information about personal lives. While some HCNs share personal information in order to develop the relationship and trust, this is usually done with caution.

1) 'knowing' in relationships affect HCN assessments of needs and capacities, and thus their decision-making

2) relationships require time and continuity (interaction); the need to build and maintain relationships may affect decisions.

3) relationships may enhance the chance that HCN personal feelings might negatively impact decisions, reducing a client/family's access to care

4) relationships may enhance the chance that personal feelings might positively influence decisions about access

Thus, while the trust and knowing fostered within relationships can have practical benefits, HCNs also spoke of needing to maintain relationship boundaries – in essence these are boundaries of the appropriate nursing role, determined in part by the limitations to home nursing care service.

Lastly, this study identified another way in which 'relationships' influence access to care, that has less to do with nurse's decision-making, and more to do with decisions made by families and clients. That is, trusting relationships increase the chances that clients and families will ask for and accept help; they will also trust the nurses' assessments about what levels and types of services they do and do not need.

These and other emerging findings from this research will be used to develop guidelines to inform and support nurses' decision making about access, as well as to inform the development of health services and policies that improve access to palliative care.

Recommendations

The 20 recommendations contained in this report call attention to the importance of (a) relationship building, (b) HCN decision making, and the (c) organizational context of home care nursing practice in palliative care. Recommendations arise from the research team's interpretation of the data and include those elements that study participants suggested are needed to enhance access to and quality of care at the end of life. Home care nurses and health authority decision makers also participated in three discussion groups and were asked to comment on the implications of the findings and assist with generating policy and practice recommendations. Through this process, and our own understanding of the study results, a number of principles were identified to guide our recommendations:

- Needs of the clients and families served by palliative home care are often acute, complex, and require HCNs to respond to changing needs.
- HCNs must play an integral role in all stages of strategic planning around best practices for home-based palliative care.
- A 'health authority wide' approach to the identification and development of best practices for home-based palliative care should include all jurisdictions, urban and rural.

- Given the inter-professional nature of palliative care practice, a collaborative, team approach to the development of best practices for home-based palliative care is essential

Our recommendations focus on the three themes from the data: (A) Relationship Building; (B) Decision Making; and (C) Organizational Context.

(A) Relationship Building

A central finding of this study was the importance of relationship building between home care nurses (HCNs), clients and families. According to HCN participants, such relationships were crucial for supporting effective HCN decision-making about access grounded in the patient and family experience. The relationships promoted the HCNs ability to assess and predict patient/family needs and capacity, respond to changes, prevent and avert crisis, working towards achieving patient and family goals. In particular, HCNs emphasized the importance of establishing and maintaining trust, as well as 'knowing' clients and families. Family caregivers also emphasized the importance of HCNs having up to date information about their situation. In the discussion groups, there was general agreement that relationship building is valued both among practitioners and management (although understood somewhat differently in the two groups). Relationships help HCNs to 'know' clients and families, helping the HCN to make appropriate assessments about needs and capacities, and related decisions about access. It is important to support continuity of care and to ensure time for 'knowing' and relationship building is available.

Participants who spoke about the importance of relationships pointed out that such relationship building and developing trust took time, sometimes over several visits. Participants said that the first visit with new clients and families in palliative care was often the most important one for setting the foundation for a 'good' relationship. One positive outcome of this 'front loaded' relationship building work is that it supports families more effectively and often avoids overly time-consuming visiting at times of transition. According to participants, the time taken for visiting varies between home care offices, between nurses, and is valued to varying degrees among nurses and managers. Establishing a standard of practice related to the expected outcomes of initial visits was one suggestion to develop consistency and recognize the importance of relationship building work in home care nursing practice.

Given the importance of relationship building, HCNs felt that the need to complete the range of forms on intake actually hindered their ability to establish or maintain relationships. In this regard, discussion group participants spoke of how some offices allow HCNs to complete forms on a less regimented, more flexible basis, i.e., gathering preliminary information over the course of the first few visits rather than expecting all forms be completed on the initial visit. In the absence of flexibility there is increased risk that the completion of documentation forms can 'drive the visit,' becoming the focus of nursing practice rather than the client/family (and using the documentation forms as a tool for communication).

Recommendations:
Given the foundational basis of relationships within palliative care practice in the home, processes, practices and policies used in home health (as well as existing clinical decision making frameworks)

should be examined using a 'relationship lens.' That is, what supports relationship building and impedes it? An analysis such as this would provide direction to strengthen structures to support HCNs and FCGs in their work to support the dying at home.

1. Undertake an analysis of palliative home care processes, practices and policies using a 'relationship lens'.
2. Acknowledge and define relationship building as a core competency in palliative home care nursing practice, and define strategies to support the development of this competency.
3. Establish a standard of practice for HCN palliative visiting that promotes relationship building, including expectations for the initial visit (e.g., ensuring adequate time for initial visits, considering continuity of nurses in the admission phase).
4. Adopt a streamlined and flexible approach to the admission documentation process to allow forms to be completed over the first few visits. Such an approach would promote and give more time to relationship building and enhance flexibility of admission visits.

Bereavement care was viewed by HCNs as an important part of 'closing' their relationships with FCGs once the client had died. At the same time, scheduling bereavement visits was often perceived by HCNs as a luxury in a climate of fiscal restraint and full caseloads. Many HCNs suggested that bereavement visits were important to ensure the well being of FCGs; in addition, these visits also play a role in helping HCNs to gain closure on the relationship and help to prevent burnout. There are established standards of practice for home care nursing visiting for bereavement care.

Recommendation
5. Develop a standard of practice for home care nursing bereavement care, delineating the role of the home care nurse and the expected outcomes of bereavement care.

(B) Decision-Making

Access decisions are a key aspect of clinical decision making in home care practice, but are rarely acknowledged as such. Substantial individual variation in decision-making processes also exists in this regard. Such variability leads to creative problem solving, but decision-making can be challenging without a common frame of reference. Study findings validate concepts contained in the *Home Care Nursing Frequency of Visiting Decision Making Tool* that was implemented in Fraser South in 2003, and suggest ways to refine and further develop the tool. Despite the potential for tools to be useful in making decisions about HCN visiting and scheduling, no tools were identified that support the processes used in home care offices to make HCN assignments or scheduling of nursing visits. Development of such tools should take into account the client/family 'story' and be balanced with resources available in individual home care offices. As well, documentation and communication (continuity of information) was identified as a key influence on HCNs' abilities to build and maintain relationships (and therefore make good decisions), particularly in the absence of staff continuity. Having access to client/family information contributes greatly to 'knowing' the client and family. Thorough, accurate, yet condensed documentation is required to increase efficiencies, particularly for home care offices that have fewer resources (e.g., in rural settings).

Recommendations

6. Acknowledge that access decisions are a key aspect of clinical decision making in home care, requiring a clear description of the skills and abilities involved in access decisions. Support is needed for the development of this competency with decision making tools, processes and education.

7. To strengthen access decision making, use the research findings to modify the *Decision making Tool for Home Care Nursing Visiting (2003);* Implement the revised 2003 decision making tool across home health offices and then evaluate its utility for informing clinical decision making about access.

8. Review and revise the process of determining the daily home care nursing assignment that both considers the effect on relationship building and includes consideration of the rationale the HCN uses to predict the date and time for the client's next visit.

9. Revise the documentation and communication systems, as needed, to support HCNs in their assessment and decision-making.

10. Utilize technological advancements (such as: mobile technology aids) to enable HCN to have the right information about palliative client at all contacts.

Making decisions about eligibility for palliative services was an area that HCNs said created tension when there was a lack of clarity when a client should receive palliative service and at what level, such as for those clients with advancing non-malignant diseases. Study findings suggest that clients with chronic illness not designated as palliative may have less access to home care nursing services than those who are as palliative. The needs of palliative home care clients tend to be prioritized above the needs of non-palliative clients because it is perceived that those who are palliative have greater needs. This is likely because palliative care services have traditionally been directed toward the advanced cancer population where disease trajectories are more predictable than those with non-malignant disease. Though many participants believed that such prioritization was a reasonable approach to guide decision making, some felt that it disadvantaged certain client groups, and lead to inequities.

11. Acknowledge the tension that home care nurses are experiencing in relation to accessing palliative services for clients with advancing chronic illness.

12. Review the issues of chronic illness and the implications for home care service delivery criteria to address the palliative care needs of this population.

13. Refine policies outlining service eligibility criteria according to chronic illness trajectories including cancer, to support HCN access decision-making.

(C) Organizational Context

Home care nurses described continuity of care as a significant factor influencing relationship building and access decisions. This was a common issue that arose in both interviews and within the discussion groups. In the current care delivery system of generalist HCN practice, continuity of home care nursing can be difficult to achieve. Participants identified that change in the current care delivery model is needed to support continuity. Interview and discussion group participants had a number of ideas of how continuity of care could be improved. It was suggested to aim for an ideal number of 'regularly' visiting HCNs per family, as challenges to continuity of care arise when there is too many care providers. Specialist home care nursing practice was another suggestion. The literature and our data suggest that

generalist models of practice, particularly when serving complex populations, are not always ideal; as such, many of the issues that our report brings forward might be best addressed by considering alternate care delivery models within home health.

Recommendations
14. Review the structures and processes of the home care delivery system for palliative patients in relation to the ability to support continuity, knowing and relationship building.
15. Review the literature and current practice models in order to identify home health care delivery models that promote relationship building, continuity, and safe, ethical practice.
16. Consider how care delivery changes can be made to enhance care for palliative clients and families.

Nurses make decisions in the context of a workload that most of them describe as too large and ever increasing, with little 'wiggle room.' Some participants expressed concern about the changing nature of home care practice, increased complexity of care and increased workloads. There was strong support for scheduling visits not just on the basis of efficiency and standard estimates, but also considering the nurses' knowledge of the client and family. Participants described the Fraser Health Home Care Point System as being operationalized differently across offices and concern that it does not match current practice reality. Discussion group participants were concerned that the points system worked better for non-palliative clients, and less so for palliative clients and families, where there is greater unpredictability, arising from emergency situations and unanticipated needs (hence a need for flexibility as palliative patients change). The points system can equalize and balance workloads between nurses if points are meaningfully used. Even so, the assignment scheduling system needs to allow opportunities for flexibility and change made in context of the needs of the patient and family and considering the HCN/patient family relationship. Some offices have more flexibility than others. Flexibility affords the ability to shuffle workloads, which appears to be more of a possibility in larger offices with more staff. Different strategies may be needed in smaller offices. Thus, there is a fine balance between standardization and flexibility to be compassionate and continue to offer high quality care. Even when home health management is perceived by HCNs as supportive, limitations in staffing resources pose larger barriers to available care.

While HCN participants clearly articulated the ways in which relationships are important for access to and quality of care, they also noted the risks involved in establishing relationships with clients and families (for instance, the risk that negative or particularly positive feelings in relationships might affect access decisions). Coupled with the inherent risks associated with relationship building work, HCNs

work within a system where workloads are increasingly overwhelming, highly complex and require responsiveness. Participants suggested that in most cases nurse burnout is not caused by the palliative work (e.g., grief, etc.) but by the context in which the work is carried out (i.e., system resources; increased acuity of clients, etc., continuous pressures regarding training).

Study findings suggest that HCNs use a number of strategies to manage their increasing workloads such as skipping breaks, working overtime, or contributing unpaid work for clients and families. Because of this, the potential for burnout is high and efforts to prevent the deleterious effects of burnout should be implemented. Opportunities should be provided to HCNs to allow them to openly discuss not only workload and system issues that influence their work-life balance but they also require opportunities to discuss issues related to personal-professional boundaries and the challenges and rewards of establishing relationships with clients and families. Such opportunities would support HCNs to handle the inherent complexity of relationships that occur within the home setting and within palliative care in particular and could potentially lead to the identification of creative strategies to address workload issues to guard against nurse burnout. HCN need to be involved in creating systems that will support HCN decision making about visits and managing the daily assignment.

Recommendations

17. Conduct a literature review of community-based "work-load" scheduling systems including the Fraser Health *Home Health Points System,* as it applies to the palliative home care population to see how current practices support HCN decision making. Such a review should address how current scheduling and the *Fraser Health Home Health Points System* include relationship building work.
18. Review nursing structures, policies, and practices to examine their implications for nurse burnout.
19. Provide opportunities to HCNs to openly discuss personal-professional boundaries and the HCN-client-family relationship.

Participants noted that dying at home may not be an achievable choice for some people in more rural and remote areas, where resources such as hospitals, access to HCNs and increased reliance upon palliative volunteers are part of a 'system' with fewer resources overall. HCNs expressed a deep sense of responsibility when a client's transitions cannot be addressed in the home and they must be admitted to hospital. Smaller geographic centres face particular challenges as well as notable gaps in access (fewer staff, longer distances, less home support available).

Recommendation

20. Retain levels of flexibility in health authority wide policies to take into account the resource environment between different home care offices and geographic areas.

Conclusion

Access to at-home care continues to be a major problem for dying Canadians and their FCGs. The role of HCNs as gatekeepers of access to care will become increasingly critical as resources are stretched in home care. HCNs occupy a pivotal position within the health care system and are uniquely situated at the front lines with intimate clinical knowledge of the palliative home care situation. They play a key role in decisions related to service allocation and in influencing access to home nursing care. Understanding the factors that HCNs take into account when making decisions and examining their encounters with FCGs in palliative care has helped to generate knowledge concerning the complexities of access, the factors shaping HCNs' decisions and inform the development of health services, policies, and decision making guidelines aimed at improving access to care for patients and FCGs in palliative care.

Appendix A: Questions Used for Think Aloud Recordings and Interviews

Modified Think-Aloud Interview Guide for Home Care Nurses

The Modified Think-Aloud (MTA) is a technique that has been used extensively with nurses to understand their decision making in everyday practice. It is a tape-recorded inventory of decisions that nurses make in the context of providing care to patients and family members. It provides information consisting of brief narrative statements on the components of the decision making process as well as the precipitating situation and outcomes of the decision and the contextual factors that influence decision-making.

One of the objectives of this study is to understand the factors that you take into account when you make decisions about the need for an amount of home care nursing services that patients and their family caregivers will receive at the end of life. In the next 2 weeks, we would ask that you record at least 4-5 episodes where you have to make such decisions. These decisions do not have to refer to the same patient/family caregiver. If you are able to record decisions for different patient/family situations, that would provide us with examples of the range of situations that you encounter in your everyday practice and give us a sense of the many factors that may be taken into account when you make decisions. We would ask, however, that you refrain from using patient or family member names in order to protect their identify and that you do not do this exercise while in the presence of palliative patients or their family caregivers.

Please consider the following guiding statements/questions when completing your MTA for each decision making episode:

1. Please tape record your thoughts regarding the following General Category of Home Care Nurses Visits for Palliative Patients and their Family Caregivers at the End of Life:

   • Perception of your role in providing home nursing care to this patient/family caregiver to support dying at home

2. Please tape record your thinking during decision making with your patient/family caregiver regarding the following:

   • Briefly describe your recent visit to the palliative patient/family caregiver (without identifying their names).
   • What was the reason that you went to visit them?
   • Were there any particular patient and/or family circumstances that precipitated the visit? If so, describe these circumstances.
   • Were there any particular patient and/or family circumstances that you encountered during your visit? If so, please describe these circumstances.

3. During your visit, did you make any decisions?

- What was the decision(s) that was made?
- What was the context of the decision (i.e., Who was there? Who was involved in the decision-making process? What was happening at the time that the decision was made?)
- What were the factors that influenced your decision(s)?
- What was the choice of action taken?

4. Please record your thinking during decision making related to the next nursing visit and/or referral to another location:

- Did you make a decision about when next to visit? If so, when is the next visit?
- How much time have you allotted for the next visit? (e.g., 30 minutes, 1 hour, 2 hours)?

Please provide the following details regarding decision making related to the next nursing visit:

- Why was the decision made?
- What was the context of the decision (i.e., Who was there? Who was involved in the decision making process? What was happening at the time that the decision was made?)
- What were the factors that influenced your decision?
- What was the choice of action taken (i.e., twice/day visits, daily visits, weekly visits, etc.)

Did you make a decision not to provide a nursing visit but rather to refer the patient from home to another location (e.g., emergency, acute care, hospice)?

If yes, please provide the following details regarding decision making related to referral of the patient from home to another location:

- Why was the decision made?
- What was the context of the decision (i.e., Who was there? Who was involved in the decision making process? What was happening at the time that the decision was made?)
- What were the factors that affected the decision to refer to another location?
- What was the choice of action taken? That is, what was the outcome for the patient/family caregiver?

1. Are there considerations other than the patient and family's needs that influence your decision making? If so, please describe these considerations.

2. Is there anything else that you want to add about home care nurses' decision making in palliative care situations that is not included in these questions? If so, please record your thoughts.

Note: there was no guide for the post-Think Aloud interviews, as the questions were developed based on the recordings

Key Informant/ Opinion Leader Interview Guide

1. What are the most pressing concerns within the home care sector that influence the care provided to palliative patients and their family caregivers?

2. In your experience, what precipitates the need for home care nursing services with this patient/ family population?

3. What do you see as the most pressing issues that home care nurses face when making decisions about the need for and amount of service provided to palliative patients and their family caregivers at the end of life?

4. In your experience, what influences people's access to home care nursing services?
   Probe: Are there issues specific to palliative care patients and their family caregivers?
   What is your understanding of the issues that family caregivers face in seeking home care services on behalf of the patient?
   Are there broader organizational issues that influence access to care?

5. What would be needed to make home care nursing services as accessible as possible for palliative care patients and their family caregivers?

Home Care Nurse Indepth Interview Guide

1. Tell me, **what it is like to work with palliative clients and families in home care**?

2. Describe a situation **where your relationship with the family caregiver went well**. *(Probes: Why did it go well? Why was that a good relationship? What is it about a relationship that makes it good?)*

3. Describe a situation **where your relationship with the family caregiver did not go well/difficult or challenging** (Probes: Why *did it not go well? What is it about a relationship that makes it not go well?)*

4. Are there some family caregivers **you enjoy working with** more than others? *(Probe: Why? What was it about the interaction that made it enjoyable/positive)*

5. Are there some family caregivers **you don't particularly like working with/that are difficult**? *(Probe: Why? Differences compared to those you enjoy working with)*

6. **Tell me about building relationships with family caregivers** *(Probes: what does it involve? What makes it easy? What makes it difficult?)*

7. **What affects family members' ability to get help from home care nursing services, including home support?** (referring to both the initial access to the program and ongoing access to home care nursing.) *(Probes: what affects/facilitates/barrier? Some nurses have talked about the first visit being*

particularly important, what do you think about that? Family members' perceptions – is it an issue?)

    a. Is there anything about the way the family might interact with home care nursing that might affect the help that they would get?(*Probe: how would you handle that situation?*)

    b. *Any* broader health care policies or systems influencing their ability to get help? *E.g. the bed shortages in acute care influence ability to influence hospital services.*

    c. What influences your own ability to provide care and support to family caregivers?

8. *Is there something unique about a patient being palliative that changes the way in which HCN's practice? (Probes: What is different between palliative and nonpalliative? If more help or visits are needed, is more available because the patient is palliative? Are special concessions made because the person is palliative? Why? Any exceptions to this?)*

9. Tell me a bit about **how you assess the capacity of a family caregiver** to provide palliative care at home? Followup question: Specifically, **how do you know if they will be able to cope well or not?**(*Probes: what cues, or instincts, communications; emotional capacity; how do they 'check it out'*)

    d. As a HCN where do you learn these kinds of skills? (*probes: formal or informal 'training'*)

10. Many nurses have talked about the importance of "knowing" the client and family and that this assists with decision making. **For you, what does it mean to "know" the family?** (*probe: initial visit in particular? How do you determine how much info they already have about resources; who is the decision-maker*).

    a. Can you describe a situation where you felt you knew the family? *(probe: what contributed to this?)*

    b. Can you describe a situation where you felt you did not know the family? *(probe: what contributed to this)*

11. Is there **anything else** that you would like to tell me about your relationships with family caregivers?

Family Caregiver Indepth Interview Guide

1. *Throughout this interview, we are going to be talking about your experiences in providing care at home, generally.* So, to start off, **how and why did home care nursing become involved?** (probes: Who requested/ arranged for it?)

2. **How would you describe your (overall) experience with home care?** (probes: how many HCNs did you have, were some more involved for others, how often were visits, who initiated visits).

3. **How would you describe your relationships with home care nurses?** Probes: did you feel you had a 'relationship' with them; how many, and:

    Describe a good relationship you had with a homecare nurse (probes: why; did you feel known; elicit detail when emotional support mentioned, such as what in particular was supportive; what qualities or behaviours of good HCNs?)

    Describe a poor relationship you had with a home care nurse (probes: why; elicit detail when conflicts are mentioned)

4. Generally **were you able to get home care nursing help when you needed it?** (Probes: specific instances where you found it difficult to get help; generally was there enough help; was what you got helpful)

5. **What influenced whether or not you asked for help from the HCNs?** (probes: any times they remember specifically choosing not to contact HCNs for help, and why; raise the idea of perceiving the HCNs were busy, not wanting to burden them, other reasons?).

6. In general **how prepared did you feel for providing care** for _____ towards the end of his/her life? (probes: in what ways did you feel prepared, and why; did HCNs play a role)

7. *Concluding:* **Is there anything else** that you would like to tell me about your relationships with the home care nurses?

Appendix B:
Sampling, Data Collection and Analysis Methods

To answer the research questions, several sets of qualitative data were collected between May 2006 and June 2008.

Sampling, Recruitment and Data Collection

29 HCNs completed modified "Think Aloud" (MTA) recordings, and participated in post 'Think Aloud' interviews in-person, about one week after the recording.

> The MTA is a tape-recorded inventory of decisions that individuals make as they occur in the context of their everyday life. It provides qualitative data consisting of brief narrative statements on the components of the decision making process as well as the precipitating situation and outcomes of the decision and the contextual factors (such as micro and macro social contexts) that influence decision-making. The MTA has been used extensively in the study of nurses' decision-making.

HCNs for this component of the study were recruited from all 15 home health offices in the health authority, through recruitment posters in the office; the study was also introduced at five hospice palliative care meetings with HCNs, and an email was sent to all home care nurses[1] in the health authority. For HCNs to be eligible for the study, they were required to be (a) registered nurses who are employed by Fraser Health and who (b) have practiced in home care for >1 year, and who (c) work a minimum of 10 shifts per month.

Nine "key informant opinion leaders" knowledgeable about the home care system (and specifically about palliative home care nursing practice) **were interviewed by phone** (see Appendix A for interview guide); these interviewees represented different levels of health authority administration. Sampling was purposive (based on suggestions from the co-investigators) and based on the following criteria: the individual must (a) be knowledgeable about home care nursing practice, (b) have an understanding of the wider social contexts in which HCNs practice, and/or (c) be familiar with the complexities involved in providing palliative care at home. These individuals were sent letters of invitation; if they declined to participate, we sought another individual in a similar position.

> This key informant/opinion leader data was supplemented with data from five home care Team Leaders who were also interviewed (and completed a brief questionnaire).

27 HCNs completed in-person interviews focusing on "a family caregiver's access to care" (see Appendix A for interview guide). Five of these volunteers had also participated in the "Think Aloud" component of the research. HCNs for this component were recruited through the same methods as for the Think Alouds (above); in addition, a newsletter invitation was also distributed to home health offices.

26 bereaved family caregivers completed in-person interviews about their experiences and relationships with home care nursing staff. Using the Fraser Health hospice palliative care database, a Fraser Health employee who was also hired by the research project acquired a list of patients who had died in the last 3-6 months in the health authority.

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[1] There are approximately 400-500 HCNs in the health authority, not including casuals. Approximately 240 HCNs are FTEs.

Eligible FCGs: (a) had lost a family member/friend within the past 3-12 months and who (b) received home care nursing services within Fraser Health. Additionally, FCGs were (c) at least 18 years old (d) be able to speak English and, (e) reside in the study setting. We chose to interview bereaved FCGs because we have learned from previous research that many current FCGs are reluctant to discuss their concerns with either the health care system or individual health care providers at a time when they are receiving and in need of health care services.

A letter of invitation was mailed to all of the family caregivers identified by the database for those on the list. If the family caregiver contacted the project agreed to participate, the research assistant arranged an interview (see Appendix A for interview guide).

Analysis

As the data were collected and transcribed, analysis occurred simultaneously and informed later portions of the data collection. The transcribed audio data were analyzed with techniques appropriate to qualitative methodology: specifically, for each of the above sets of data,

a) Transcripts were re-read multiple times to identify recurring, converging and opposing themes and patterns, key concepts, illustrative examples from the data and possible linkages to theory.

b) Then, a preliminary coding scheme was developed and used to categorize and code the first set of interviews, then evaluated and revised (e.g., some categories being expanded or collapsed). The revised coding scheme was applied to interviews within the computer software package NVivo (a program used for organizing and grouping data).

c) In some cases, a visual diagram was created to illustrate how the categories seem to relate to each other; this visual diagram evolved over time, based on feedback from the investigative team, as the analysis of the interview data progressed.

d) As the analysis proceeded, the emerging findings were used to inform and revise the interview questions for future interviews, to enhance descriptive and interpretive validity.

e) Data contained within each code or theme were then reviewed, and the pieces of data compared, linked and contrasted, for further refinement of the analysis and conceptual framework.

Appendix C: Demographic Characteristics of Participants

Think Aloud Participants: n=29

Age:	Range: 40-63 years	Average: 50 years
Gender:	28 females, 1 male	
Education:	27 diplomas, 2 BSN, 2 with other degrees	
Certification:	3 with C.N.A. HPC certification, 3 with other certification	
RN experience	Range: 5-41 years	Average: 22 years
HCN experience	Range: 1-31 years	Average: 6.5 years
Years in current office	Almost all were in the same office for their whole HCN career	
Years doing palliative care	Almost all reported doing palliative care through their whole HCN career	
Years in current position	Most had been in the same position for their whole HCN career	

Key Informant Opinion Leader Participants: n=9

Age:	Range: 40-60 years	Average: 52 years
Gender:	8 females, 1 male	
Education:	1 diploma, 2 baccalaureate degrees, 2 medical degrees, 4 Master's degrees	
Years in health care	Range: 26-40 years	Average: 32 years
Years in leadership in home care	Range: 6-35 years Average: 16 years	
Years in current position	Range: 1-12 years Average: 6 years	

Team Leader Participants: n=5

Age :	Range: 33-55 years Average: 48 years
Gender:	5 females, 0 males
Education:	4 baccalaureate degrees, 1 Master's degree
Years in Fraser Health	Range: 2-13 years
Years in current office	Range: 2 months to 7 years
Years in current position	Range; 2 months to 1 year

Home Care Nurse Participants (Indepth Interviews):   n=27

Age:	Range: 31-62 years	Average: 49 years
Gender:	26 females, 1 male	
Education:	24 diplomas, 3 BSN, 1 with another degree	
Certification	7 had C.N.A. HPC certification	
RN experience	Range: 9-37 years	Average: 24 years
HCN experience	Range: 1-28 years	Average: 9 years
Years in current office	2/3 had been working in FH in the same office for their whole HCN career	
Years doing palliative care	Almost all reported doing palliative care for their whole HCN career	
Years in current position	Half had remained in the same position through HCN career	
Employment status	13 full time, 12 part time, 2 casual	

Family Caregiver (FCG) Participants: n=26

FCG age range:	Range: 32-87 years	Average: 58 years
FCG gender:	22 females, 4 males	
FCG education:	Range: from elementary school to post graduate studies. The majority graduated high school	
FCG ethnicities (may be>1):	Canadian=17, Scottish/English/Irish=12, European=7, U.S.A.=1, Chinese=1	
FCG marital status:	All but one were married or widowed	
Relationship to deceased person:	Wife=15, Husband=4, Daughter=7	
Lived with deceased person:	Yes=24, No=2.	
Length of time living with the deceased person:	Range: 6 weeks to 62 years	
Characteristics of deceased client:		
Client age at death:	Range: 45-89 years	Average: 71 years
Client gender:	7 females, 19 males	
Ethnicities of client (may be>1)::	Canadian=10, Scottish/English/Irish=14, European=8, Chinese=1	
Services:	- All had home nursing care ranging from once, to every two weeks, to daily. - Half had home support. - Half had rehab services. 4 had the Hospice Palliative Care team. - Most were involved with the Cancer Clinic. - Only one family had meal services. 1/3 had used transportation services (including ambulance). - Half used counseling services. 80% had a medical specialist (including oncologist). - Half had at least one visit by the Hospice Palliative Care physician. - Only two families had volunteer services. - Half had visited Hospital Emergency at least once. 80% were on the BC Palliative Benefits Plan.	