Beyond their own family caregivers, home healthcare nurses play a pivotal role in caring for those dying at home. However, deciding the timing of the next visit for these patients and their families is not straightforward. The Palliative Care: Determining Next Home Care Nurse Visit *decision guide supports clinicians in their decision-making process of planning visits to most effectively meet the needs and goals of patients and families during the final months of life.*

CE 2.4 HOURS Continuing Education

Applying Research INTO PRACTICE

A Guide to Determine the Next Palliative Home Care Nurse Visit

Al's Story

Al, a 78-year-old man diagnosed with colon cancer metastatic to the liver and peritoneum, was admitted to home healthcare for palliative services 4 weeks ago. A care plan is in place to manage right upper quadrant (RUQ) pain related to liver metastases with prescribed opioid regular and breakthrough doses. Al's pain has been mild at 2/10 at rest, requiring one breakthrough opioid dose every 1 to 2 days. Ascites from metastatic disease has not required drainage for the past 2 months. Al has moderate congestive heart failure; controlled with regular cardiac medications and a self-management plan. Aware of illness red flags, Al understands when he should call the nurse between regularly scheduled visits. Since his admission, his palliative performance scale (PPS) has been

©JOSE OTO/BSIP

Della Roberts, MSN, RN, CHPCN(C), Barbara McLeod, MSN, RN, CHPCN(C), Kelli I. Stajduhar, PhD, MSN, RN, Terry Webber, BPN, RN, CHPCN(C), and Kya Milne, BSN, RN, CHPCN(C)

stable at 60% (reduced ambulation, needing help with housework and occasionally with self-care). Al's goal is to die at home, if possible. He lives alone with his daughter Anne living close by. She has care-giving capacity, providing regular support and taking Al to appointments. Anne plans to take time off work and stay with her father "when the time comes."

Today is your first visit with Al and you find his PPS has dropped from 60% at his last visit 2 weeks ago to 50% today. His activity is reduced to mainly sitting and he needs help with showering. Having taken a break through opioid dose 2 hours ago, his RUQ pain is 4/10. Al says the waistband on his pants feel tight. You measure his abdominal girth, but there is no baseline in the chart for comparison. His chest is clear and he has no shortness of breath. His weight is up 2 lb over the past week. Al has called Anne and she is taking her father to his physician tomorrow. Al says he wonders if his cancer is catching up to him. You increase the home support worker hours to provide daily help for Al's personal care and send his physician an assessment from your visit, but are unable to speak with Anne.

How does the home healthcare clinician decide when to next visit? What factors should be taken into account to base this decision? Approaches to cases like this vary between clinicians and recommendations on when to next visit patients in similar circumstances differ. Inconsistent decisions about timing of visits, a lack of explicit practice references, and the potential for poor outcomes prompted clinicians and managers to request a guide to support decision making. Blending practice wisdom and research, two clinical nurse specialists led an initiative resulting in an evidence-informed decision guide to assist clinicians to determine when to next visit a palliative patient and family. This article shares the decision guide as well as its development, application, and the implications of using the guide in practice.

Describing the Practice Context

The "Palliative Care: Determining Next Home Care Nurse Visit" decision guide (Figure 1) and guide instructions (Figure 2) support clinicians with next visit decisions for patients receiving palliative care services from the home healthcare program in Fraser Health, British Columbia, Canada. A patient with a medical prognosis of months rather than years is eligible for palliative services at home. Similar to other Canadian home healthcare contexts, visit determination is based on clinician judgment of patient needs balanced with the availability of home health resources rather than policy that limits the number of home care nursing visits available for a patient. Creation of this explicit decision-making guide contributes to development of consistent next visiting practices.

Clinicians found the practice wisdom guide useful in decision making but highlighted a number of areas where the guide lacked sufficient clarity. Was there a ranking in importance and weighting of the assessment factors? If one factor was highly ranked, did that correspond to a higher level of risk or were more factors required to increase the risk? Clinicians' practice questions triggered the realization that evidence was needed to inform further development of the guide to answer these questions.

Background Literature

People with terminal illness spend most of time in their last months of life at home, regardless of where they ultimately die (Gomes & Higginson, 2013). Although family caregivers and home health services are critical to care at home, home care nurses play a pivotal role (Ward-Griffin & McKeever, 2000). Deciding how often nurses should visit, however, is not straightforward; dying at home is a complex process where change is anticipated and transitions are the norm. Palliative patients' conditions can rapidly change; uncontrolled symptoms can cause severe distress (Downing et al., 2010). Family caregivers can become overburdened with providing care while dealing with their own impending loss (Stajduhar et al., 2008). The care situation can become unmanageable in the absence of appropriate and timely access to home care nursing,

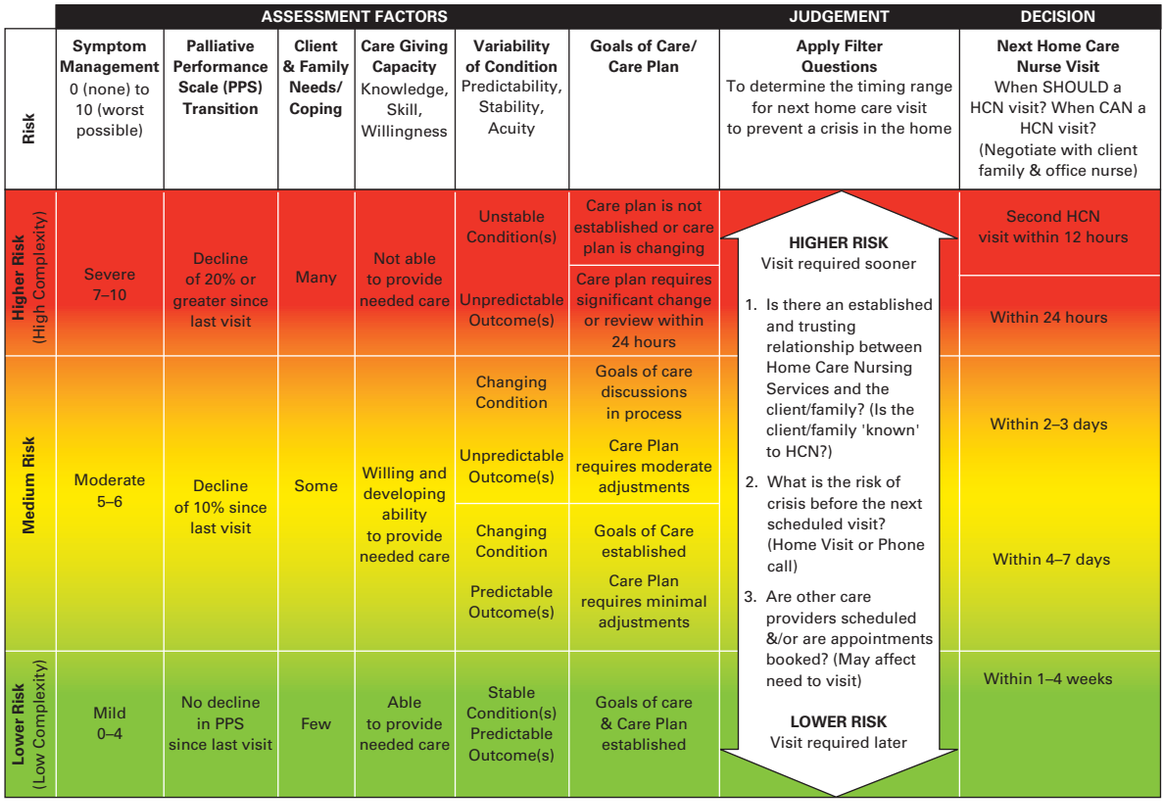

Figure 1. Palliative care: Determining next home care nurse visit. Reprinted with permission.
Note. HCN = home care nurse.

particularly for patients expected to die within weeks or months of time (Stajduhar, 2003). In this changing context, clinicians must determine the optimal timing of the next visit.

Clinicians use anticipatory thinking to extend their view of care beyond the present (Gillespie & Peterson, 2009). Planning the next visit involves many cues and interpretations, and capacity for this decision making varies. The predictive judgement required to schedule the next visit is a competency new home healthcare clinicians need to acquire.

In contrast to expert clinicians who draw upon intuitive knowledge, novice clinicians depend more heavily on rules to guide their decision making (Benner, 1984). When they do not have confidence in their decision making, novices rely on more experienced colleagues or may avoid these situations (Tanner, 2006). Revealing the processes of decision making by experts and the factors influencing their decisions can help the novice gain greater understanding of clinical decision making (Benner, 1984; Tanner, 2006). A decision guide is one strategy to make this knowing explicit; encouraging reflective practice, promoting consistency, and improving outcomes of care (Medves et al., 2010).

Practice Wisdom and Guide Development

Although the literature is replete with studies on nurse decision making, we found no references that provided specific guidance for decisions about when to time home care nursing visits for palliative patients. Recognizing that expert clinicians have this knowledge, we decided to create a decision guide based on "practice wisdom." McLeod's (2000) earlier work about nursing decision making lent credibility to our process of bringing experienced nurses together to describe the factors they considered when planning the timing of the next home visit as a base for a decision-making guide. The guide developed outlined assessment factors to be considered in determining

Purpose:

To inform clinical assessments, judgments, and decisions to determine the next home care nursing visit for patients and families receiving palliative services.

Instructions:

The next visit is determined by reading the guide from left to right.

Risk:

Risk is the probability of an immediate negative outcome to health, safety of client/family, secondary complications, and/or crisis in the home. The level of risk indicates the timing range of the next scheduled visit.

- High Risk (Red)
- Medium Risk (Yellow)
- Low Risk (Green)

The higher the risk the sooner the visit (home visit or telephone call) is required.

Decision-making process:

1. Determine the level of risk for each of the six assessment factors considering the indicators described.

Symptom Management: Highest intensity of the entire patient's symptom(s) using a rating scale of 0 to 10 where 0 (none) to 10 (worst possible). Mild, moderate, severe (Zelman, 2005).

Palliative Performance Scale (PPS) Transition: Patient's general physical functioning and the change occurring. (Victoria Hospice Society, 2006).

Client & Family Needs and Coping: Holistic needs and coping abilities.

Caregiving Capacity: Caregiver knowledge, skill and willingness to provide needed care.

Variability of Condition: Degree to which a patient's condition or situation changes or is likely to change. Considerations include predictability, stability, and patterns of change. (CRNBC, 2005)

- Predictability: the ability to predict outcomes in the client situation.
- Stability: the status of the client illness and trajectory.
- Acuity: the degree of severity of a client's condition and/or situation.

Goals of Care/Care Plan: Patient and family expressed wishes for care. Plan to support the needs and goals.

2. Determine the overall risk.

The highest level of risk of any one assessment factor reflects the corresponding level of risk: Red/Yellow/Green.

3. Make a judgment about the degree of risk.

Ask the 3 filter questions to determine if the timing of the next HCN visit should be sooner or later within the Risk category range.

(1) If the relationship with home care services is weaker, a visit is needed sooner.

(2) A sooner visit is required if the risk of a crisis in the home is high.

(3) If other providers can address the identified needs/goals of the patient and family a later home care nurse visit may be possible.

4. Make a decision for the next visit.

Collaborate to determine the date to schedule the next visit based on what is possible for the patient, family, and capacity of the home health office.

Figure 2. Guide instructions. Reprinted with permission.

a level of risk. Each level of risk was associated with a corresponding visiting frequency.

Clinicians found the practice wisdom guide useful in decision making but highlighted a number of areas where the guide lacked sufficient clarity. Was there a ranking in importance and weighting of the assessment factors? If one factor was highly ranked, did that correspond to a higher level of risk or were more factors required to increase the risk? Clinicians' practice questions triggered the realization that evidence was needed to inform further development of the guide to answer these questions.

Nursing Research and Guide Development

We needed to better understand the cues nurses use to make a decision to next visit and their decision-making process. The palliative clinical nurse specialists partnered with university-based researchers to design a qualitative research study to better understand the factors clinicians take into account when making decisions about the need and amount of service for patients and families at the end of life. Twenty-nine home care nurses participated in think-aloud interviews recording their decision-making process about planning visits, and were then interviewed to clarify points that arose out of the think-aloud analysis. Study findings revealed a complex practice environment where clinicians considered a number of cues to inform predictive judgments about the need, amount and timing of home care nursing visits (Stajduhar et al., 2011b).

Decision Guide Refinement

Although findings of the research validated a number of the concepts of the original decision guide, key factors of symptoms, care-giving capacity, variability and relationships, as well as features of the process of decision making described by study participants, were missing. A team of palliative care clinicians and expert home care nurses applied the research findings and decision-making theory into the previous practice wisdom guide to create a refined evidence-informed decision guide. After piloting the new decision guide in one home healthcare office and making final modifications, the guide was implemented across all 13 Fraser Health Home Healthcare offices.

The Decision Guide

The "Palliative Care: Determining Next Home Care Nurse Visit" decision guide informs clinical assessments and judgments to assist in the planning of the next home care nursing visit, to effectively support the needs and goals of patients and families, and to prevent crises in the home. At the conclusion of each visit a decision is required about the timing of the next visit. The colors in the decision guide demonstrate the dynamic nature of decision making and aid the clinician to match the degree of risk with the urgency of the visit; from low risk to medium risk to high risk. The guide reflects the perspective that decision making is not a linear problem-solving process, but a complex process situated within a greater context (Gillespie & Peterson, 2009).

The assessment phase establishes a baseline of knowing by referencing the key factors considered in forming a predictive judgment about the timing of the next visit. The more foundational knowledge of the patient and family the nurse has, the better the nurse can create a balanced decision (Stajduhar, 2011a). These factors include features of the patient's clinical presentation and disease, as well as the illness experience, strengths, and coping resources of both the patient and the family (Tanner, 2006). Indicators for each assessment factor align with one of the three levels of risk.

The judgment phase guides a fluid process of further exploring the risk of crisis in the home before the next visit by filtering the level of risk, initially determined by the assessment phase, through consideration of three trigger questions. The relationship of the patient and the family with home care services influences the timing of the next visit. A stronger relationship often indicates that the patient will call home health if needs change between scheduled visits. Those with weaker relationships require a sooner visit time. As well, interprofessional team involvement and coordination are strong filter considerations in predicting the timing of the next nursing visit. The up and down arrow in the judgment column acknowledges this process of interpretation.

In the decision phase, the guiding questions are "When should we next visit?" and "When can we next visit?" These guiding questions highlight a step that is typically invisible but important in decision making, where the clinician chooses an

Table 1. Case Application: Determining the Next Visit in Al's Story

1. Determine the level of risk for each factor assessment.

	Factor Assessment	Risk Level
• *Symptom Management:*	RUQ Pain 4/10 Shortness of breath 0/10 Tightness in abdomen—mild	Low
• *PPS transition:*	PPS declined 10% since last visit	Medium
• *Patient and family needs/coping:*	Needs are changing; new coping skills may be required	Medium
• *Caregiving capacity:*	Family caregiver is willing and capable	Low
• *Variability of condition:*	Condition changed; outcomes unpredictable	Medium
• *Goals of care/care plan:*	Goal to die at home; no plans for care in last days; care plan needs adjustment	Medium

2. Determine the visit timing in relation to risk.

The factor in the highest risk level determines the overall risk level, and for Al the assessment factors are in the green and yellow zones. While Al's risk is within the medium or yellow zone of 2 to 7 days, the variability of Al's condition with unpredictable outcomes guides the timing of the next visit to be at a higher priority, within 2 to 3 days.

3. Make a judgement: Consider the filter questions:

• *Is there an established relationship with home care services?* Yes

With a stronger relationship with home health, Al and Anne are more likely to call a clinician if Al's needs for support change before the next planned visit.

• *What is the risk of crisis before the next scheduled visit?* Moderate

The reason for Al's change in condition has yet to be determined. His heart failure may be contributing to his symptoms. If his symptoms are related to ascites and these are managed, his functional status could improve. Or his disease burden may be increasing, leading to functional decline and increased symptom burden, reflecting a closer time to dying. These unknowns reflect a moderate risk of crisis.

• *Are other healthcare providers scheduled or appointments booked?* Yes

Al has an appointment with his family physician tomorrow and home support workers are visiting daily to help with his shower. These healthcare providers will also be addressing some of Al and Anne's needs.

4. Decision: A HCN should visit in 2 days.

Because there is a moderate risk of crisis with a potentially changing condition, the sooner date in the range of 2 to 3 days is chosen.

5. When should/can a HCN visit?

- Negotiation with the patient: Although the clinician offers to come to Al's home in 2 days, he says close friends are coming to his home for an important visit. He'd prefer the nurse visit in 3 days. The nurse suggests a telephone visit in 2 days, with a possible home visit the following day. Al agrees and says if his condition continues to change, he'll have Anne call the office.
- Negotiation with the home healthcare office: There is capacity for a telephone visit in 2 days with flexibility for a home visit, if necessary.

6. Decision for next HCN visit: Telephone visit 2 days.

Notes. HCN = home care nurse; PPS = palliative performance scale; RUQ = right upper quadrant.

The assessment phase establishes a baseline of knowing by referencing the key factors considered in forming a predictive judgment about the timing of the next visit. The more foundational knowledge of the patient and family the nurse has, the better the nurse can create a balanced decision. These factors include features of the patient's clinical presentation and disease, as well as the illness experience, strengths and coping resources of both the patient and the family. Indicators for each assessment factor align with one of the three levels of risk.

appropriate action considering the role of sharing information and the possibility of collaboration (Gillespie & Peterson, 2009). The final question guides the nurse to consider these contextual variables in negotiation with the patient, family, and the resources of the home healthcare office.

Application of the Decision Guide to Al's Story

We return to Al's story and apply the decision guide to determine the next visit in Al's story, assuming that the reader is the clinician in the second half of the case study (Table 1). Although not a linear process, for teaching purposes we'll move through the case in a stepwise process as outlined in the guide instructions.

Implications

Clinicians find the decision guide very useful in practice. Through practice huddles, clinical rounds, and education sessions, they describe how the guide helps prioritizing patient visits, provides a common language for case discussion, and enables nurses to explain decision-making rationale. Nurses use the guide to describe clinical situations indicating a need for additional staff or overtime. As an education tool, use of the guide supports development of the next visit competency and communication between mentors and novice nurses regarding their decision making.

Although developed specifically for nurses working with patients expected to die within months of time, the tool has broader practice implications. The decision guide provides valuable guidance for next visit decisions for patients with chronic life-limiting illnesses where the timing of dying is less predictable, such as those with congestive heart failure or chronic obstructive lung disease, and has the potential to inform visit timing decisions for other clinicians such as rehabilitation therapists. The guide can inform decisions beyond when to next visit. Recently, the guide was modified to support decisions about who is the most appropriate nurse to visit palliative patients, a licensed practice nurse or a registered nurse. Finally, the format and processes representing the critical thinking process captured in the guide provides a template to articulate other complex decision processes in home health.

Limitations

Formal evaluation of the effectiveness of the tool is underway. As the decision guide has generated great interest in the clinical practice community with many requests to share this work, we are publishing the tool while undertaking the quality-improvement process. A follow-up publication on the evaluation will be forthcoming.

Conclusion

The decision guide creates a clear process for determining the next visit, enabling nurses to better schedule timely visits to support patients and families at home during the final months of life. Novice clinicians in particular benefit from the explicit description of the decision-making process involved in this complex clinical decision. The decision guide for next visit is an example of how the application of nursing research into home healthcare practice can build evidence-informed knowledge and promote consistent clinician decision making for the next visit along the novice to expert continuum. ☗

***Della Roberts, MSN, RN, CHPCN(C)**, is a Clinical Nurse Specialist, End of Life Care Program, Fraser Health, Surrey, British Columbia, Canada.*

***Barbara McLeod, MSN, RN, CHPCN(C)**, is a Clinical Nurse Specialist, End of Life Care Program, Fraser Health, Surrey, British Columbia, Canada.*

***Kelli I. Stajduhar, PhD, MSN, RN**, is an Associate Professor, Centre on Aging, School of Nursing, University of Victoria, Victoria, British Columbia, Canada.*

***Terry Webber, BPN, RN, CHPCN(C)**, is a Nurse Clinician, End of Life Care Program, Fraser Health, Surrey, British Columbia, Canada.*

***Kya Milne, BSN, RN, CHPCN(C)**, is a Nurse Clinician, End of Life Care Program, Fraser Health, Surrey, British Columbia, Canada.*

The authors gratefully acknowledge the support of several nurses who participated in the refinement of the guide (Pat Loitz, Sue Mole, Jaspal Olak, Sally Sprecher, and Jenny Wright). They also acknowledge Dr. Michael Downing of Victoria Hospice for his leadership in tool development in palliative care and his advice with our guide. The study that informed development and refinement of the guide was funded by the Canadian Institutes of Health Research. At the time of this study Dr. Stajduhar was funded by research career awards from the Canadian Institutes of Health Research and the Michael Smith Foundation for Health Research.

The author and planners have disclosed no potential conflicts of interest, financial or otherwise.

Address for correspondence: Della Roberts, MSN, RN, CHPCN(C), Clinical Nurse Specialist, End of Life Care Program, Fraser Health, Suite 400, Central City Tower, 13450-102nd Ave., Surrey, British Columbia, Canada V3T 0H1 (della.roberts@fraserhealth.ca).

DOI:10.1097/NHH.0000000000000018

REFERENCES

Benner, P. (1984). *From Novice to Expert: Excellence and Power in Clinical Nursing Practice.* Meno Park, CA: Addison-Wesley.

College of Registered Nurses of British Columbia Practice Standard. (2005). *Assignment between nurses.* Retrieved from https://www.crnbc.ca/Standards/Lists/StandardResources/414AssignbetweenNursesPracStd.pdf

Downing, G. M., Lesperance, M., Lau, F., & Yang, J. (2010). Survival implications of sudden functional decline as a sentinel event using the palliative performance scale. *Journal of Palliative Medicine, 13*(5), 549-557.

Gillespie, M., & Peterson, B. L. (2009). Helping novice nurses make effective clinical decisions: The situated clinical decision-making framework. *Nursing Education Perspectives, 30*(3), 164-170.

Gomes, B., & Higginson, I. (2013). Evidence on home palliative care: Charting past, present, and future at the Cicely Saunders Institute—WHO Collaborating Centre for palliative care, policy and rehabilitation. *Progress in Palliative Care, 21*(4), 204-213.

McLeod, B. (2000). *Expert nurses' decision-making regarding intravenous patient controlled analgesia.* Unpublished Master's Thesis. Department of Nursing, University of British Columbia, Vancouver, BC, Canada.

Medves, J., Godfrey, C., Turner, C., Paterson, M., Harrison, M., MacKenzie, L., & Durando, P. (2010). Systematic review of practice guideline dissemination and implementation strategies for healthcare teams and team-based practice. *International Journal of Evidence-Based Healthcare, 8*(2), 79-89.

Stajduhar, K. I. (2003). Examining the perspectives of family members involved in the delivery of palliative care at home. *Journal of Palliative Care, 19*(1), 27-35.

Stajduhar, K. I., Funk, L. M., Roberts, D., Cloutier-Fisher, D., McLeod, B., Wilkinson, C., & Purkis, M. E. (2011a). Articulating the role of relationships in access to home care nursing at the end of life. *Qualitative Health Research, 21*(1), 117-131.

Stajduhar, K. I., Funk, L., Roberts, D., McLeod, B., Cloutier-Fisher, D., Wilkinson, C., & Purkis, M. E. (2011b). Home care nurses' decisions about the need for and amount of service at the end of life. *Journal of Advanced Nursing, 67*(2), 276-286.

Stajduhar, K. I., Martin, W. L., Barwich, D., & Fyles, G. (2008). Factors influencing family caregivers' ability to cope with providing end-of-life cancer care at home. *Cancer Nursing, 31*(1), 77-85.

Tanner, C. A. (2006). Thinking like a nurse: A research-based model of clinical judgment in nursing. *Journal of Nursing Education, 45*(6), 204-211.

Victoria Hospice Society. (2006). *Palliative Performance Scale (PPSv2): Medical Care of the Dying* (4th ed., pp. 120-121). Victoria, British Columbia, Canada: Victoria Hospice Society.

Ward-Griffin, C., & McKeever, P. (2000). Relationships between nurses and family caregivers: Partners in care? *Advances in Nursing Science, 22*(3), 89-103.

Zelman, D. C., Dukes, E., Brandenburg, N., Bostrom, A., & Gore, M. (2005). Identification of cut-points for mild, moderate and severe pain due to diabetic peripheral neuropathy. *Pain, 115*(1-2), 29-36.