

Résumé

Questions méthodologiques en matière de recherche portant sur la pratique infirmière en soins palliatifs

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Cette étude intégrative a comme but de décrire les recherches dirigées par des infirmières et des infirmiers depuis le milieu des années 90 dans le domaine des soins palliatifs et des soins de fin de vie. Elle vise également à identifier les progrès et les défis méthodologiques tout en proposant des stratégies pour appuyer le développement de la recherche en sciences infirmières. Une étude des bases de données a révélé la publication de 121 rapports de recherche entre 1995 et 2003. Nous avons inclus des études dont l'auteur principal était une infirmière ou un infirmier, dont le centre d'intérêt était soit la pratique infirmière, soit les attitudes du personnel infirmier à l'égard des soins palliatifs et de fin de vie. Nous avons constaté qu'un nombre relativement réduit d'études ont inclus des patients, que les méthodes utilisées dans la collecte des données présentaient certaines lacunes et qu'il y avait peu d'études destinées à évaluer les soins infirmiers palliatifs. L'accent mis sur l'approche interdisciplinaire en soins palliatifs peut empêcher les infirmières et les infirmiers d'examiner l'efficacité des interventions infirmières. Cet aspect, ainsi que le rendement, doivent faire l'objet d'une plus grande attention afin de garantir les meilleurs résultats pour les patients et leurs familles.

Mots clés : soins infirmiers palliatifs, soins de fin de vie, étude intégrative, méthodes de recherche, recherche en sciences infirmières.

Methodological Issues in Researching Palliative Care Nursing Practice

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The purpose of this integrative review was to describe the research conducted by nurses since the mid-1990s on nursing practice in the context of palliative/end-of-life care, identify promising methodological developments as well as methodological challenges, and propose strategies to support the development of this field of nursing research. A search of databases resulted in 121 research reports published between 1995 and 2003. Studies were included if the lead author was a nurse and the focus was nursing practice or nurses' attitudes about providing palliative or end-of-life care. Relatively few studies included patients, there were limitations in the data-collection methods used, and there was a lack of studies evaluating palliative care nursing. An emphasis on the interdisciplinary nature of palliative care may be hindering nurses from examining the effectiveness of nursing interventions. Increased attention should be given to examining the efficiency and effectiveness of nursing interventions to ensure the best outcomes for patients and their families.

Keywords: palliative care nursing, end-of-life care, integrative review, research methods, nursing research

As the development of palliative care services has become a priority in Canada, the difference that nurses can make to palliative care patients and their families has taken on greater significance. It is therefore timely to review the research on nursing practice in the context of palliative care and the methodological issues in this field of research. There is growing acceptance of palliative care as an interdisciplinary health service with a role to play throughout the trajectory of life-threatening disease, albeit with increasing input towards the end of life. The definition of palliative care, therefore, emphasizes the mutual reliance among representatives of different disciplines, and is shifting from a clear focus on end-of-life care to a broader view of services needed throughout the disease-illness trajectory. These changes make it increasingly difficult to define a "palliative care patient" and appropriate contexts in which to develop and assess palliative care nursing interventions and programs. The focus of this paper is nursing research that addresses aspects of nursing care related to the terminally ill who, although perhaps still receiving treatments for symptom control, are in the last days, weeks, or months of their lives.

Background

Benoliel (1983) conducted one of the first reviews of nursing research and terminal illness, spanning the years 1969 to 1981. She concluded that the body of research was fragmented and comprised largely descriptive studies. Benoliel recommended that greater attention be given to the integration of sound conceptual frameworks within research designs. Although nurses had made a significant contribution to the knowledge base on nurses' experiences of death, patient and family adaptation to death, and environmental and social processes affecting responses to death and terminal illness, there was a dearth of research addressing nursing practice interventions (other than psychosocial).

In the 1990s several systematic reviews were undertaken to describe developments in palliative care research conducted by nurses, as well as methodological trends and issues (Bailey, Froggatt, Field, & Krishnasamy, 2002; Froggatt, Field, Bailey, & Krishnasamy, 2003; Richardson & Wilson-Barnett, 1995; Wilkes, Tracy, & White, 2000). An increase was observed in the number of palliative care studies conducted by nurses in the 1990s. Although the focus was descriptive research, both quantitative and qualitative methods were used. Concerns were raised about the quality of some of the research, such as the limited use of nursing theories or frameworks and the lack of rigour in some of the qualitative research. Important developments during this period included the use of mixed-method designs, an interest in practice-based research, evaluation and patient-focused research, and the use of qualitative methods to study patient outcomes where nurses have an effect on care.

Nurses have also been involved in comprehensive reviews of palliative care research conducted by nurses and others (Corner, 1996; Johnston & Abraham, 1995). Issues in palliative care research identified in these reviews included the development of palliative care research as a specialized field, the disparate focus of palliative care research due to its relevance for many areas of health care, and issues related to conducting research with the dying. The predominance of descriptive studies, the narrow scope of evaluations, the lack of consensus on standard measures, and slow development of appropriate measures for palliative care research, particularly outcomes measures, were highlighted as methodological issues in palliative care research. Recommendations for advancing this field of research included increased use of flexible, multi-method designs, consensus on standard measures, creation of databases, and increased collaboration through interdisciplinary research.

Nurses have been important contributors to discussions about the unique issues and challenges of conducting palliative care research with families and children (Davies, Chekryn Reimer, Brown, & Martens,

1995; Davies, Steele, Stajduhar, & Bruce, 2003; McClement & Woodgate, 1998). Nurses have also described issues related to conducting qualitative research in the context of palliative care (Beaver, Luker, & Woods, 1999; Davies et al., 1995) as well as the special considerations demanded by the vulnerability of palliative care patients and their families (Dean & McClement, 2002).

In summary, nurses have been active contributors to the field of palliative care research and to the development of research approaches and methods. Yet there is no recent review of nursing research focusing on palliative care nursing practice in order to describe progress and identify methodological issues and challenges. The purpose of this integrative review was to describe the research conducted by nurses since the mid-1990s specifically on palliative/end-of-life nursing care, to identify promising methodological developments and challenges, and to propose strategies for supporting the development of this field of nursing research.

Methods

We searched CINAHL, MEDLINE, Sociofile and Web of Science databases to retrieve all the available literature published on palliative care nursing. The following keywords were combined: hospice and palliative nursing or palliative care; end of life or terminal care or palliative care; hospice or hospices; and terminal care. We also requested documents mapped to nursing attitudes or nursing experience/practice in palliative care, eliminating all editorials and commentaries. The search was confined to English-language empirical studies published between 1995 and 2003. We also limited the search to studies whose lead author was a nurse. This search strategy returned 467 articles, which were then reviewed for inclusion/exclusion criteria. Excluded were articles that focused specifically on family experiences of caring for relatives with terminal illnesses, patient experiences at end of life, nursing education, and experiences of health-care providers other than nurses, as well as literature reviews and organization audits. Studies that considered diverse perspectives were included if findings directly related to nurses were clearly reported. A pool of 121 published research studies met these criteria.¹ A data-extraction form was developed to systematically capture information about each study. Data were entered into a data file to assist with the summarizing of findings.

The most frequent source of studies was nursing journals, the majority being published in the *International Journal of Palliative Nursing* ($n = 38$) and the remainder in 27 different publications, including the *Journal of*

¹ A complete list of studies included in this review is available from the authors.

Table 1 Characteristics of Studies Included in the Integrative Review

Design Characteristics	Research Category			
	Professional Nursing Roles and Issues (n = 70)	Nursing-Care and Health-Care Context (n = 16)	Descriptions of Nursing Practice (n = 20)	Evaluation of Nursing Practice/Interventions (n = 15)
Palliative care population				
• adult, general	45	4	13	4
• child/adolescent	4	0	0	0
• cancer	7	2	7	9
• HIV/AIDS	1	0	0	0
• other	3	0	0	2
Research design				
Qualitative (n = 71)	19	8	10	2
• generic qualitative				
• grounded theory	6	0	5	0
• phenomenology	10	1	0	0
• ethnography	2	3	0	0
• case study	4	0	0	1
Quantitative (n = 38)	23	3	3	2
• descriptive/correlational				
• comparative survey	2	0	0	0
• experimental/ quasi-experimental	0	0	0	5
• pilot study (n = 5)	0	1	0	4
• mixed method (n = 7)	4	0	1	2

<p>Sampling method</p> <ul style="list-style-type: none"> • purposive • theoretical • convenience • random • stratified • other (e.g., whole population, systematic sampling) 	<p>27 1 21 2 0 19</p>	<p>0 0 3 1 2 0</p>	<p>10 1 8 1 0 0</p>	<p>4 0 6 2 0 3</p>
<p>Data collection^a</p> <ul style="list-style-type: none"> • standardized measures, unmodified • standardized measures, modified • investigator-developed measures • interviews, face-to-face • focus groups • observation • physiological measures 	<p>4 4 61 42 6 6 0</p>	<p>0 0 15 7 6 3 0</p>	<p>1 3 16 13 1 2 1</p>	<p>10 1 4 7 1 0 3</p>
<p>^aMultiple data-collection methods were used in some studies.</p>				

Advanced Nursing ($n = 8$), the *Journal of Clinical Nursing* ($n = 4$), *Nursing Ethics* ($n = 4$), and *Cancer Nursing* ($n = 6$). Non-nursing journals included the *Journal of Palliative Care* ($n = 2$), the *European Journal of Cancer Care* ($n = 2$), the *American Journal of Critical Care* ($n = 4$), and *Hospice Journal* ($n = 2$). Most investigative teams were made up entirely of nurses ($n = 99$; 82%); 21 multidisciplinary research teams were identified, and these included investigators from medicine, the social sciences, and information studies. We were unable to determine the composition of the research team for one publication. Over half of the reviewed studies were conducted in the United States and the United Kingdom ($n = 75$, 62%); 20 (16%) were conducted in Australia and the remainder in Canada (5%), Europe (4%), and other countries (13%), including Japan. Eighty of the studies (66%) were published since 2000.

Findings

The studies included in the review were classified according to target study population and design characteristics (see Table 1). The majority of the studies (63%) focused on the provision of palliative/end-of-life care for adults, 30% focused specifically on cancer patients with advanced disease, and only four focused on nursing terminally ill children or youth. Generic qualitative methods were represented in the majority of the qualitative studies ($n = 39$), followed by grounded theory ($n = 11$), phenomenology ($n = 11$), ethnography ($n = 5$), and case-study methods ($n = 5$). Among the quantitative studies reviewed, the majority were descriptive/correlational ($n = 31$; 25%); the remainder included five experimental or quasi-experimental designs, two comparative surveys, and seven mixed-method designs. Among the quantitative studies reviewed, random or systematic sampling approaches were used in only 13 (out of 33). The use of relatively small convenience samples was evident in some studies. In the qualitative studies, the adequacy of the sampling strategy was rarely addressed. Underrepresented in this body of research were palliative care patients and families from ethnocultural groups, children and adolescents, and those dying from diseases other than cancer.

In the 38 quantitative studies reviewed, less than half ($n = 17$) used standardized measures for data collection. The majority of studies ($n = 21$) used investigator-developed surveys and measures. Psychometric evaluations were limited to assessing content validity using expert panels and estimating reliability coefficients.

The foci of the studies were classified according to four topics: descriptions of professional nursing roles and issues related to the care of the dying ($n = 70$), descriptions of nursing care of the dying as influ-

enced by health-care context ($n = 16$), descriptions of nursing interventions/practices ($n = 20$), and evaluations of nursing interventions/practices ($n = 15$). Examination of the study designs and methods used with each of the topics revealed some interesting patterns.

Professional Nursing Roles and Issues Related to Care of the Dying

This category comprised the majority of the studies conducted since 1995 by nurse researchers, and included primarily exploratory, descriptive studies ($n = 70$). Qualitative designs were used to describe nurses' suffering, stress, moral distress, and grief; nurses' responses to ethically challenging situations (e.g., requests for assisted suicide); and the ways in which nurses found meaning in their work. Studies describing nurses' perceptions of palliative care services, nursing roles and professional issues (e.g., related to ethical issues at end of life) included both qualitative and quantitative designs. In this group of studies, only four used mixed designs.

Given the focus of these studies, samples comprised mainly nurses (76%, $n = 53$); 41 of the 70 studies used semi-structured interviews; one phenomenological study used open, unstructured interviews; 28 used questionnaires (predominantly incorporating investigator-developed measures); and a few used observational methods ($n = 6$) and focus groups ($n = 6$) in combination with this primary method. Several studies used innovative approaches to enhance data collection. For example, Wilkes, Boxer, and White (2003) used faxed photographs of malignant wound cases as prompts in telephone interviews with nurses caring for patients with these types of wounds. In another interview study, poetry about death and dying was used to help nurses reflect on their experiences (Larkin, 1998). A fictional case study was used to elicit responses and facilitate the interview process in a study of nurses' opinions regarding assisting or hastening a patient's death (Pierce, 1999).

Descriptions of Nursing Care of the Dying as Influenced by Health-Care Context

This set of 16 studies provided descriptions of the management of nursing care for dying patients in a variety of settings while accounting for influencing factors (e.g., norms related to disclosure of information about death and dying, the involvement of relatives, clinical practice environments, and relationships among health-care providers). With the exception of three survey studies, this group of studies used generic qualitative research designs.

Among the qualitative interview-based studies, nine collected data from nurses only. All three ethnographies employed observational methods, whereas eight qualitative studies principally used interviews and

focus groups. Three studies used institutional records as a data source, one of which was based principally on analysis of nursing discharge summaries.

Descriptions of Nursing Interventions/Practices

Twenty studies focused on nursing interventions and practices, particularly those developed over time by clinicians to address clinical problems. The underlying objective of this research was to identify and describe interventions so they could be formally incorporated into practice and evaluated in a variety of contexts. This group of studies used qualitative methods, with four exceptions. Survey methods were used to describe the use of hope-engendering interventions by nurses (Herth, 1995) and nursing practices used to manage malignant wounds (Wilkes, White, Smeal, & Beale, 2001). A descriptive correlational design was employed in a secondary data analysis to identify patterns of nursing interventions used to care for dying patients (McCorkle, Hughes, Robinson, Levine, & Nuamah, 1998). Finally, one researcher combined nurses' diaries and hospital-record data in a mixed-method design to describe the provision of telephone support by nurses to bereaved relatives of palliative care patients (Kaunonen, Aalto, Tarkka, & Paunonen, 2000). This group of studies was characterized by diversity of the samples.

All but three of the qualitative studies relied exclusively on individual or group interview data to describe nursing interventions. Only two studies used observation. In one of these, an initial period of participant observation during home-care visits was used to identify questions for inclusion in interviews with nurses to collect rich descriptions of nursing practice (Morgan, 2001). In the second study, participant observation of nurse-patient interactions in two palliative care units was used in conjunction with interviews with nurses and patients to identify strategies used by nurses to support the involvement of patients in decisions about their care (Botorff et al., 2000). Brief, informal conversations with both patients and nurses were included to elicit additional data. In this way, some patients who were unable to participate in in-depth interviews were included in the study.

Worthy of mention is the interesting approach used by McCorkle et al. (1998) to identify patterns of nursing interventions. Her study entailed analysis of comprehensive narrative records of nursing interventions maintained by nurses as part of a larger study. This team used Grobe's Nursing Intervention Lexicon and Taxonomy, a seven-category classification scheme, to code all descriptions of nursing activities. This approach allowed them to identify and describe the types of nursing interventions used by advanced practice nurses in home-care settings for older cancer patients in the dying phase.

Evaluation of Nursing Interventions/Practices

There were relatively few evaluations of nursing interventions led by nurse researchers. This small group of studies ($n = 15$) included evaluations of specific nursing interventions such as the use of quality-of-life scores to prompt the planning of patient-centred care (Hill, 2002) and attempts to link the spectrum of services provided by specialized palliative care nurses to patient and family outcomes. Only five evaluations of palliative care nursing services using experimental designs were identified, in addition to two mixed-method designs. Other studies included an evaluation of the validity of nurses' assessment of the symptom experiences of hospice patients using correlational methods, a case study of the nurse practitioner's role in palliative care, an evaluation of an after-hours telephone-support program for hospice patients, and two qualitative studies. Pilot studies ($n = 4$) to evaluate protocols prior to conducting full-scale evaluations were also included. In the only two longitudinal studies, outcomes were assessed at various points following admission to palliative care, and with follow-up assessments up to 25 months after the patient's death in two studies (Corner et al., 2003; McCorkle et al., 1998).

Although determining and measuring the quality of end-of-life care is a complex undertaking, researchers attempted to identify and measure nurse-sensitive outcomes for palliative care (Corner et al., 2003; McCorkle et al., 1998; Williams & Sidani, 2001) using quality of life, spousal distress, anxiety, and depression, as well as nurse, patient, and family accounts of the care provided. A few studies used multiple sources of data to determine outcomes. For example, in addition to using standard quality-of-life measures, Corner et al. collected and analyzed data from patient and caregiver interviews, clinical information, and nurses' records. These data were compiled into a single narrative for each patient and subjected to thematic analysis. When outcomes of care were evident, they were identified and coded as positive, equivocal, or negative. This approach allowed for the description of multiple outcomes for each patient at different points in time, and served to avoid some of the problems associated with examining outcomes among individuals whose condition worsens. The evidence provided by patients was deemed to be the strongest, followed by that provided by caregivers, other health professionals, and finally nurses. Once instances of care were identified, the balance of outcomes identified for each case was calculated to gain an overall picture for each patient. Positive outcomes related to improvement in physical symptoms or emotional state, the receipt of information/advice, feeling supported by the Macmillan nurse intervention, explicit acknowledgement of the value and/or beneficial quality of the

nurse's care, and an expressed belief that the presence of the nurse improved the quality of care. Negative outcomes were related to the absence of any of the above or the absence of improvement following application of the Macmillan intervention. In instances where there was an absence of information on outcomes or where the complexity of the patient's condition precluded assessment of the nurse's contribution, the outcome was categorized as equivocal. This innovative approach to capturing nurse-sensitive patient outcomes offered new insights into the complex ways in which nurses benefit palliative care patients and points to the limitations of relying on single indices to capture such benefits.

Discussion

The findings of this review indicate that there is a small but growing body of research, by nurse researchers, investigating the practice of palliative care nursing. Although nursing studies describing patient and family experiences at the end of life may inform research on palliative care nursing practice, these studies were not included in the review. Furthermore, the body of research included in the review does not represent all of the studies evaluating palliative services provided by nurses. The increasing emphasis on the interdisciplinary nature of palliative care has led some nurses to focus on the contributions of the palliative care team rather than on nursing interventions or nurse-sensitive outcomes. Although disentangling the unique contributions of nursing care is a complex matter, the evidence-based practice movement and the demand for professional accountability have prompted the development of research approaches that may hold relevance for palliative care nursing (Doran, 2003).

Descriptive research is still the dominant design used by nurse researchers studying palliative care nursing practice. The importance of this research should not be underestimated, because descriptive, exploratory qualitative research has the potential to uncover new knowledge about various dimensions of palliative care nursing and provide the foundation for the development of measures and interventions that address the needs of palliative care patients and their families. Furthermore, it has been suggested that the preponderance of generic qualitative descriptive methods is not uncommon in practice disciplines and offers comprehensive summaries that focus on the *who*, *what*, and *where* of the phenomena of interest (Sandelowski, 2000). Nevertheless, very few of the qualitative studies covered in this review focused on developing explanatory theory or on linking inductively derived concepts to construct theories.

Previous methodological reviews have regarded the use of mixed methods as a promising development in nursing research on palliative care, because their flexibility and ability to capture a wider range of dimensions make these methods particularly suited to palliative care. It appears, however, that mixed-method studies remain under-utilized. Furthermore, there is a lack of critical perspective in evaluating the influence of social structures and processes on the provision of palliative nursing. The relatively small number of studies that included patients, the limitations associated with data-collection methods, and the lack of evaluation of palliative nursing interventions highlight the need for innovative research approaches. This field of research could benefit from enhanced sampling and recruitment strategies, enhanced data collection, and the evaluation of palliative care nursing practice.

Sampling and Recruitment

Few of the studies acknowledged recruitment as a limitation in their research, although this issue is implicit in the reports of other studies. Even with detailed planning as to the identification of potential cases, careful consideration of the relevance of eligibility criteria, and use of methods to keep refusal rates low, difficulties can arise in obtaining samples (McMillan & Weitzner, 2003). In order to enhance accrual in palliative care research, investigators are being encouraged to examine such topics as individuals' responses to invitations to participate in research, factors that influence their decision whether to participate as well as their experiences as participants, the best times to request consent, predictors of impaired decision-making capacity, and interventions to improve decision-making capacity (Addington-Hall, 2002; Casarett, 2003; Koenig, Back, & Crawley, 2003). The inclusion of assessments of the impact of the research on participants is also likely to be useful in informing the development of research designs that minimize the burden for participants. In his study, for example, Hudson (2003) incorporated a four-item questionnaire to assess the impact of research participation on family caregivers of dying cancer patients. Nurses with expertise in qualitative methods could make a significant contribution to the investigation of patients' and bereaved relatives' participation in research. In addition, some palliative care researchers are proposing innovative approaches to both recruitment and informed consent. Two promising approaches are the incorporation of screening questions into routine intake procedures, to identify patients who are willing to participate, and the use of advanced consent.

The use of screening questions to distinguish between individuals who may and may not be interested in research could be useful in palliative care settings, to ensure that researchers approach only those

who are receptive. Crowley and Casarett (2003) evaluated the usefulness of two screening questions (for symptom-related research and disease-modifying research) in the intake process of a palliative care clinic. Patients were presented with both questions and were asked to explain their answers. They were told that affirmative responses to either question could result in their medical file being reviewed to determine their eligibility for research participation. Because recruitment typically begins with an assessment of interest in general terms, the usefulness of screening questions merits further evaluation for nursing studies. Exploration of a wide range of factors that may influence interest in research participation could provide direction for recruiting specific groups as well as for modifying designs to address patient concerns about participation. This approach may also serve to make clinicians feel more at ease about recruitment and to reduce gatekeeping.

Advanced consent procedures have been proposed for palliative care research, to address problems with patient accrual associated with fluctuations in cognitive status and the rapid course of many terminal illnesses (Casarett, Knebel, & Helmers, 2003; Rees & Hardy, 2003). Rees and Hardy conducted a feasibility study of an advanced consent process to enable research with patients in the terminal phase. The process entailed the provision of information about the study to eligible patients upon admission and the provision of an information sheet to those who expressed interest in the study, after which, during a follow-up visit by a nurse, patients were asked to sign their informed consent. At each subsequent admission, patients were asked if they were still interested and re-signed the consent. If the patient was unable to sign and relatives indicated there was no reason why the patient would have changed his or her mind about participating, the previous consent was considered valid. If the patient subsequently developed the clinical problem to be addressed in the study (in this case noisy respiration), he or she was randomized. Although the ethics of advanced consent have been questioned by some, the authors conclude that the process was viable and that the refusal rate suggested patients did feel free to decline.

Data Collection

As noted in previous reviews, there is a continuing need for standard outcome measures across care settings as well as for flexibility in measurement approaches to accommodate deterioration in patient health (Davies et al., 1995; Johnston & Abraham, 1995). In particular, efforts to define and measure nurse-sensitive patient outcomes are critical. Some recent developments may provide useful approaches to evaluating the effectiveness of palliative care nursing interventions. For example, Rankin et al.'s (1998) concept of "dignified dying" and the development of new

tools such as the Abbey Pain Scale to measure severity of pain in individuals with late-stage dementia (Abbey et al., 2004) will likely enhance our ability to assess nurse-sensitive outcomes in palliative care. While acknowledging the methodological and ethical difficulties of assessing individuals prior to death, Johnston and Abraham suggest that in the final stages of life open-ended measures may be more appropriate and may facilitate participation.

In qualitative studies, the tendency to rely on interview data was identified in previous reviews of palliative care nursing research, and it appears that this situation has not changed significantly. Despite the value of interview data, the use of in-depth interviews with patients may be compromised by their level of fatigue, pain, or other illness effects and unpredictable changes in their cognitive status. Over-reliance on interview data can also limit the range of nursing practices that are identified. For example, in an unpublished pilot study to identify interventions that home-care nurses providing palliative services used to support family communication, Miller (2003) found that nurses were often unable to report details of the verbal and nonverbal behaviours that made up their approaches to caregiving; sometimes their explanations indicated a lack of awareness of their behaviours or the language to describe their actions. Morse (2000) argues that the chief mode of identifying nursing interventions is observation, particularly non-participant observation along with in-depth interviews. Observation of naturally occurring clinical practice and associated patient outcomes is lacking in the emerging body of research on nursing practice in palliative and end-of-life care. Although the collection of observational data in clinical settings is represented in the studies reviewed, no observations were carried out in home-care settings despite the shift in the delivery of palliative care from hospital to home settings. It has been illustrated that observational approaches that are sensitive and ethical and that produce rich data can be developed. Stajduhar (2001) conducted participant observations in homes where family members were providing palliative care as part of a study to describe caregiving experiences during the “dying period” and to explore the influence of health-care context on these experiences. These observations included the provision of home-care support services by a variety of health professionals. Sensitive to the burden that participation placed on families, Stajduhar offered them a choice between interviews only or observations, negotiated the number and length of observation periods, and continually renegotiated consent. The number of observations in each home varied from 3 to 10, with some patients dying soon after she became involved. Instead of positioning herself as a detached observer, Stajduhar became involved in “normal” family life by helping with household chores, conversing informally with caregivers over cups

of tea, and playing with grandchildren. Using this approach, she completed over 100 hours of participant observation with a core group of seven caregivers and an additional 30 hours with another six caregivers. Thirteen other active caregivers who did not wish to participate in home observations agreed to be interviewed.

Spiers (2002) conducted a study of home-care nursing to explore the interpersonal contexts of negotiation in 10 nurse-patient dyads, including four patients with terminal illness. To enhance comfort levels and reduce reactivity with the data-collection approach, she interviewed all patients prior to videotaping their interactions with nurses. The participant-observation role she found to be least intrusive during the data-collection visits was that of minimal participation. Spiers videotaped 31 nursing visits using a camcorder, then interviewed the nurses to elicit data on their perceptions of the visit, the main topics of conversation, nursing goals, and any communication difficulties. She returned to patients' homes to interview them about their experiences and their expectations with regard to home care. Spiers' analysis of moment-by-moment communication revealed six interpersonal contexts for negotiation, providing a framework for reconceptualizing the notion of resistance in nursing care.

Evaluating Nursing Practice

Although randomized controlled trials (RCTs) are the gold standard for linking interventions with outcomes, few were identified in this review. This may be a reflection of the well-known difficulties of conducting research with dying individuals, the resources required to conduct an RCT, and the challenges of determining and measuring outcomes of high-quality individualized palliative/end-of life nursing care. Notwithstanding the advice that nurse researchers are beginning to provide to others considering RCTs with palliative care patients and their families (Hudson, Aranda, & McMurray, 2001; McMillan & Weitzner, 2003), three additional approaches hold promise for determining the effectiveness of palliative care nursing interventions for patient outcomes. Firstly, flexible and diverse mixed-method studies need to be developed. For example, intervention studies could be enhanced by incorporating qualitative methods into the design. While maintaining the integrity of each method and ensuring a fit with the overall purpose of the research, qualitative data-collection and analysis methods can be used to describe and explain individual variation on outcome measures obtained from instruments, to ascertain the validity of outcome measures, and to clarify the nature and course of an intervention (e.g., how it is executed, the expertise and labour required to execute it, and the response to it) (Sandelowski, 1996). Nesting qualitative methods into

clinical trials cannot compensate for or salvage poorly designed or executed trials. However, as Sandelowski suggests, when physiological and psychological outcomes appear less sensitive to nursing, the use of qualitative methods in RCTs provides an opportunity to discern nurse-sensitive patient outcomes and to increase the visibility of nursing efforts.

Other approaches to RCTs could also be considered. One potentially useful approach is Qualitative Outcome Analysis (QOA), proposed by Morse, Penrod, and Hupcey (2000). This approach makes use of qualitative methods to evaluate the effect of an intervention on patient outcomes while describing the application of the intervention. What makes this approach potentially useful in the context of palliative nursing is the fact that it is premised on the dynamic and complex nature of clinical work. Multiple collection methods are used to gather data on shifts and refinements in the use of interventions as patient conditions change over time and to ensure the capture of different perspectives and aspects of the intervention's efficacy. Unlike qualitative evaluation (Patton, 1990), QOA not only provides opportunities for researchers to describe both process and outcomes, but also allows them to expand or augment interventions by including other strategies learned through the implementation process.

Finally, databases of outcomes for all recipients of nursing services in a given hospital, region, or system could be an invaluable source of information for studies on end-of-life care across all settings. Although there are complex issues entailed in establishing such databases, commitments have been made to do so in some jurisdictions. Work has also begun with regard to developing evidence-based understandings of patient outcomes that have demonstrated sensitivity to nursing care and evaluating associated measurement instruments (Doran, 2003). It is important that palliative care nurse researchers be part of these initiatives.

Conclusion

Nurses have the potential to make important contributions to the development of knowledge in the field of palliative care — knowledge that is needed to guide decisions with regard to both practice and policy. Nevertheless, nurses will likely continue to be part of interdisciplinary palliative care teams. Therefore, unless researchers identify designs and methods for capturing nurses' unique contributions to outcomes, the development of research devoted specifically to nursing interventions will be further compromised. Examining the appropriateness, efficiency, and effectiveness of nursing interventions should be a priority, in order to ensure that the best outcomes for patients and their families are achieved.

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