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McGill University School of Nursing

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GUEST EDITORIAL

Acute and Critical Care

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This issue of *CJNR* arises from a call for papers on research conducted in tertiary/high-acuity and critical care settings. Increasingly, we are recognizing that optimal management of the acutely and critically ill spans a continuum related to progression through physical locations within an acute-care institution. For example, interventions such as early goal-directed therapy for severe sepsis and septic shock emphasize the important role played by early recognition of critical illness in the emergency department (Rivers et al., 2001). Critical Care Outreach Teams (also known as Medical Emergency Teams or Rapid Response Teams) recognize the potential for critical illness to develop in any location within the hospital and the need for timely intervention.

However, critical illness also spans a continuum related to progression from the acute event to physical and neurocognitive rehabilitation, interventions to promote psychological well-being, and educational strategies for health promotion, as reported in the study by Fredericks and colleagues in this issue of *CJNR* on educational interventions for culturally diverse patients following cardiac surgery.

For non-survivors of critical illness, optimizing end-of-life care is an important consideration. The articles selected for this issue of the Journal reflect this continuum but offer greater insights into the events experienced at its end as opposed to at its beginning. Another important emphasis in the selected contributions is the role that nursing plays as one of the professions represented on the interprofessional team managing acute and critical illness. Lack of role integration and potential stressors associated with the functioning of the interprofessional team are noted.

Frank and colleagues describe a nurse-led quality-improvement intervention using a previously validated questionnaire (Canadian Health Care Evaluation Project, or CANHELP) to measure the quality of end-of-life care for patients at high risk of death admitted as acute medical inpatients. Health-care teams were informed of potential improvement opportunities identified by the questionnaire as well as patient symptom profiles using the Edmonton Symptom Assessment Scale. The study's results indicate small improvements in satisfaction with high-priority aspects of end-of-life care. However, the authors note inconsistent adherence on the part of various medical teams to recommendations made by the study nurse. Better integration of the nursing role in improving end-of-life care as part of the medical team is recommended for future study.

Using a descriptive qualitative design, Gélinas and colleagues describe stressors experienced by nurses providing end-of-life care in the intensive care environment. Using the categories *organizational, professional,* and *emotional* identified by Fillion, Saint-Laurent, and Rousseau (2003), the authors identify difficulty with interprofessional collaboration as well as a lack of continuity and palliative approach to care as major stressors.

The role of nurses in situations of conflict between family members and health-care providers in the intensive care unit (ICU) is explored in the study reported by Edwards and colleagues. Interestingly, when encouraged to tell a story about their experience of conflict, 11 out of 12 nurses gave an example from end-of-life care. Participants described their role as providing a "bigger picture" of the patient to other members of the health-care team, building or repairing relationships and building trust, and providing support to each other in the context of a highly stressful environment.

It is interesting to note that these three articles addressing the important topic of end-of-life care all identify areas of concern regarding interprofessional team functioning and the potential for conflict. Over a decade ago, Baggs et al. (1999) reported that ICUs with high levels of nurse-doctor collaboration demonstrated improved mortality rates and reduced length of stay. Lack of collaboration and hierarchical team functioning is recognized as impacting negatively on patient safety (Reader, Flin, Mearns, & Cuthbertson, 2007). In a large, multicentre international survey (Azoulay et al., 2009), end-of-life care was reported as the main source of conflict in the ICU setting due to the absence of psychological support, suboptimal decision-making or symptom control, and disregard for family preferences; the second source of conflict was poor interpersonal or general behaviour. Furthermore, intra-team conflict between ICU physicians and nurses was identified by 33% of the 7,498 respondents from 323 ICUs in 24 countries. Obviously there is a need for knowledge development to focus on interventions designed to ameliorate conflict during end-of-life care in the ICU.

The Discourse contribution in this issue of the Journal concerns the potential impact of critical illness on psychological well-being. The lead author, Mona Ringdal, has a program of research focused on the impact of memory on psychological health-related quality of life for survivors of critical illness. Based on the work of Ringdal and that of other investigators, such as Christina Jones (Jones et al., 2007), factual memory and avoidance of delusional memories related to critical illness are now recognized as influential in psychological recovery. Interventions such as the nurse-written diaries and nurse-led ICU follow-up clinics discussed in the Discourse have been widely adopted in Scandinavian countries (Akerman, Granberg-Axéll, Ersson, Fridlund, & Bergbom, 2010) but have yet to receive much attention in Canada. The promising results of a recent randomized controlled trial examining the impact of diaries on psychological functioning (Jones et al., 2010) may serve to increase interest in this intervention in Canadian ICUs. Further opportunities for research on this intervention include exploration of such issues as the mechanism by which diaries influence psychological well-being and optimal timing of diary handover to the patient and family.

I believe that over the next decade we will continue to see growth in research exploring interventions designed to improve both psychological and physical health related to quality of life in survivors of critical illness. Alongside these investigations, we need to develop and validate tools for identifying those patients most in need of follow-up interventions as well as refine tools so that they will be able to accurately detect the effects of those interventions.

It has been my great pleasure to serve as guest editor for this issue of *CJNR* and I look forward to future developments in nursing research relevant to the topics raised in the articles you are about to read.

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Discourse

Recovery After Critical Illness: The Role of Follow-up Services to Improve Psychological Well-Being

Mona Ringdal, Louise Rose

Introduction

Intensive care units (ICUs) are one of the most expensive care settings (Flaatten & Kvale, 2003; McLaughlin, Hardt, Canavan, & Donnelly, 2009), with many patients receiving highly technological life-saving and complex clinical care of reasonably short duration. Internationally, ICUs maintain high standards of care, with specialized training comprising both clinical and theoretical content for critical care nurses (Williams et al., 2007). Family- and patient-centred care, which takes into consideration the patient's wishes and preferences and promotes the patient's involvement in care decisions, is a tenet of ICU care (Glimelius Petersson, Bergbom, Brodersen, & Ringdal, 2011). The overall goal of care in the ICU, as in other health-care settings, is for patients to regain their health and well-being. It is also important for individuals to return to work after critical illness and be part of society. These goals, however, are not achieved for all patients (Ringdal, 2008).

Physical and psychological problems often arise after discharge from the ICU. Health-related quality of life (HRQoL) for ICU patients 1 year after discharge is reported to be below that for the average population (Chaboyer & Elliott, 2000; Ringdal, Plos, Lundberg, Johansson, & Bergbom, 2009), and reduced HRQoL may persist for more than 5 years (Ringdal, Plos, Ortenwall, & Bergbom, 2010). Also, patients' ability to return to work after critical illness is decreased following ICU discharge, particularly within the first year (Myhren, Ekeberg, & Stokland, 2010; Ringdal et al., 2010), leading to increased societal burden.

What interventions currently are used to optimize psychological well-being and prevent long-term psychological problems for ICU patients and their families? The purpose of this Discourse is to highlight some of the issues that impact patient recovery after critical illness, current interventions, and justifications for ICU follow-up services.

The Stress of Intensive Care

For most patients, ICU admission is unexpected, with no time for preparation, and is a frightening experience that includes pain and anxiety (Ringdal, 2008). Interviews with ICU survivors tell us that they felt vulnerable during their ICU stay and did not know what was happening from day to day (McKinley, Nagy, Stein-Parbury, Bramwell, & Hudson, 2002). Anxiety may be worsened due to patients' reduced ability to communicate their fears because of intubation and mechanical ventilation, sedation, and decreased level of consciousness (Karlsson & Forsberg, 2008). For the same reasons, communication with the patient may be limited, with relatives/significant others receiving most of the information about the patient's status. Family members are forced to consider the impact of serious illness and deal with uncertainty about the outcome. For the family, nothing is more important during the patient's admission than what is happening in the ICU (Engstrom & Soderberg, 2004) and the need to keep hope alive (Engstrom & Soderberg, 2007).

Delusional Memories and Their Impact on Psychological Well-Being

Following ICU discharge, 30% to 70% of patients report unpleasant and sometimes delusional memories (Jones, Griffiths, Humphris, & Skirrow, 2001; Ringdal, Johansson, Lundberg, & Bergbom, 2006; Samuelson, Lundberg, & Fridlund, 2006). Development of delusional memories is multifactorial. Patients often require analgesia and sedation for pain and anxiety; however, over-sedation with benzodiazepines and opioids leads to decreased factual recall of the ICU stay (Samuelson et al., 2006). Insufficient treatment of pain is common (Arroyo-Novoa et al., 2008). Also, sleep is disrupted due to ongoing care needs and this can contribute to patients' anxiety and fear (McKinley et al., 2002). Sedation strategies that target light sedation, including daily interruption, facilitate patients' awareness of their environment and enable their participation in care, resulting in decreased duration of ventilation and of the ICU stay (Kress, Pohlman, O'Connor, & Hall, 2000). However, the impact of this wakefulness on the patient's psychological well-being remains uncertain. Facilitation of increased factual memories may decrease delusional memories and reduce psychological morbidity, including post-traumatic stress disorder (PTSD) (Jones et al., 2001).

Delusional memories also are suggestive of delirium, which increases morbidity and mortality among critically ill patients (Ely et al., 2004). Although the factors that precipitate ICU delirium are still not fully understood, patient characteristics, chronic pathology, acute illness, environmental factors, and medications such as benzodiazepines and anticholinergic agents may contribute to the syndrome (Van Rompaey et al., 2009).

Decreased psychological well-being, including symptoms of anxiety, depression, and PTSD, after ICU discharge is common (Myhren, Ekeberg, Toien, Karlsson, & Stokland, 2010; Schandl et al., 2011). In fact, the psychological consequences of critical illness were first recognized in 1956, when a 3% incidence of psychosis following cardiac surgery was reported for a large cohort of patients (Bolton & Bailey, 1956). Even after 5 years, patients may experience anxiety and depression arising from delusional memories related to their ICU stay (Ringdal et al., 2010), which can have a lasting impact on HRQoL (Granja et al., 2005; Ringdal et al., 2010). It is imperative that ICU clinicians evaluate interventions aimed at reducing patients' delusional memories and associated psychological stress.

Current Interventions for Improving Psychological Well-Being After Critical Illness

Diaries as a Recovery Tool Following Critical Illness

The primary aim of patient diaries, kept during ICU admission, is to facilitate understanding of the ICU course of events for the patient and family (Bäckman & Walther, 2001). Diaries are a low-cost potentially rehabilitative intervention that promotes psychological recovery (Egerod, Christensen, Schwartz-Nielsen, & Agard, 2011). Over the last decade, research on patient diaries has been conducted in Scandinavia and other European countries, with a focus on patient, family, and nurse perspectives (Egerod, Storli, & Akerman, 2011; Knowles & Tarrier, 2009; Roulin, Hurst, & Spirig, 2007). Diaries, written in the ICU in everyday language by both nurses and patients' family members, are an important tool for initiating a conversation about the ICU experience. Also, they may contribute to the patient's recollection of events (factual memories) and are a useful debriefing tool following ICU admission (Bäckman & Walther, 2001). Diaries facilitate sharing of the patient's story and family members' feelings during the ICU stay and provide support to patients as they piece together fragmentary memories after ICU discharge (Bergbom, Svensson, Berggren, & Kamsula, 1999; Roulin et al., 2007). Diaries that contain photographs can provide strong visual images to give friends and relatives a better understanding of the individual's experience with critical illness. The benefits of diaries as identified by family members include the opportunity to put into writing the sadness and hope they experienced as well as to read about the patient's daily life in the ICU (Bäckman & Walther, 2001). For nurses, writing in the diary can be a way of forming a relationship with the patient as a person and focusing on the patient's everyday life (Gjengedal, Storli, Holme, & Eskerud, 2010). Through these mechanisms, diaries can facilitate the patient's psychological recovery (Jones et al., 2010).

There are different methods for writing diaries. For example, in some ICUs only nurses write the diary (Knowles & Tarrier, 2009) whereas in other ICUs relatives and all ICU team members are encouraged to make entries (Bäckman & Walther, 2001; Bergbom et al., 1999; Egerod, Schwartz-Nielsen, Hansen, & Laerkner, 2007). Since diaries are moderately resource-intensive, generally they are used only if it is clear that the patient will be in the ICU for more than 3 days. Patients or their relatives must consent to the keeping of a diary and the taking of any photographs. Generally, diaries begin with a case summary, including the reason for ICU admission and the current status of the patient. Content and writing style should be in lay language. Diary entries on issues important to the patient should be included. For example, events outside the ICU normally of interest to the patient, such as sporting events or relevant news items, can be included. It is important to describe the seriousness of the patient's condition and any significant progress, such as sitting up in a chair for the first time (Bäckman, 2011).

Follow-up Services

A statement in a Brussels Roundtable report in 2002 proposed that ICUs take increased responsibility for long-term outcomes of ICU survivors, including provision of ICU follow-up services (Angus & Carlet, 2003). It is important that follow-up services be patient- and family-centred. In Sweden, most follow-up services are led by ICU nurses and comprise patient diaries with photographs, patient consultation at a nurse-led clinic (NLC), and feedback about ICU survivors to ICU staff (Glimelius Petersson et al., 2011). Similar models are reported for other European countries (Cutler, Brightmore, Colqhoun, Dunstan, & Gay, 2003; Jones et al., 2010). The primary aim of NLCs is to meet the information needs of patients and family members and give them an opportunity to ask questions about the ICU stay (Glimelius Petersson et al., 2011). Diaries are handed over to the patient either upon ICU discharge or at the first follow-up visit to the NLC. Some follow-up services include a ward visit by the NLC nurse after ICU discharge but prior to hospital discharge.

Patients are generally offered up to three follow-up visits — soon after ICU discharge and subsequently at 3 and 6 months. Accompaniment by family members is encouraged. Feedback to ICU staff is facilitated via a patient follow-up book that includes a brief description of the patient's ICU stay and recovery experience as well as photographs (Glimelius Petersson et al., 2011; Samuelson & Corrigan, 2009). The

NLC model is perceived as requiring only modest resources (Glimelius Pettersson et al., 2011; Samuelson & Corrigan, 2009), as the service generally entails one to four experienced ICU nurses working part-time and consultation with the multidisciplinary team only as needed. More resource-intensive approaches include follow-up led by a physician or provided by a multidisciplinary team (Schandl et al., 2011).

ICU follow-up clinics are not a new phenomenon. In the United Kingdom, ICU follow-up clinics have existed since 1990. In a national survey of UK ICUs conducted in 2006, 30% had follow-up clinics, 55% of which were nurse-led (Griffiths, Barber, Cuthbertson, & Young, 2006). Nurse leadership of follow-up services seems to be the most prevalent model in the United Kingdom, with various methods for negotiating additional multidisciplinary services as required by individual patients. No data are available on the number of ICUs with follow-up clinics in Sweden and other countries, including Canada. The Swedish national intensive care registry (SIR) provides guidelines stipulating that follow-up services be available for all patients with an ICU stay exceeding 4 days (http://www.icuregswe.org/sv).

Table 1 ***Potential Psychological Benefits of Follow-up Clinics***

- Enhanced person-centred care to help patients move on with their life after critical illness
- Opportunity for patients and relatives to ask questions after ICU discharge
- More thorough information and explanation about the ICU stay
- Referral mechanisms for patients and relatives in serious psychological distress
- Increased feedback to staff about the long-term consequences of critical illness

Theoretical Considerations Regarding the Recovery Process

From a philosophical point of view, experiences and memories are a person's life history. They bring meaning to events and have an influence on a person's present and future life (Gadamer, 1989). When something happens that makes individuals forget parts of their own history or leaves them with memories that are bizarre or unbelievable, it may affect their everyday functioning (Ringdal, 2008). Morse's (1997) Responding to Threats to Integrity of Self theory can be used as a framework during follow-up care to understand a patient's situation after ICU discharge. This theory concerns the process of recovery from serious illness, including the meaning of the illness experience and changes experienced by the individual. It has five phases: *vigilance, disruption, enduring, suffering,* and *learning to live with the altered self.* The *vigilance* phase marks the start of the illness, when the patient suspects something is wrong; for ICU patients, this phase may begin when they regain consciousness in the ICU. With *disruption,* the patient has to hold on to life and survive. In the *enduring* phase, the patient strives to regain self; the most acute phase of critical illness is over and the patient focuses on recovery. In the *suffering* phase, the patient struggles with grief concerning his or her altered future. Finally, in *learning to live with the altered self,* the patient tries to accept the consequences of critical illness and to put the suffering aside.

Ringdal, Plos, and Bergbom (2008), in an interview study with ICU survivors, found that patients had bad and good memories in accordance with the different phases in Morse's (1997) theory. In the *vigilance* phase, bad memories, experienced early in the ICU stay, arose from feelings of anxiety and fear, disbelief about what was happening, and changing plans for the future due to the critical illness. Bad memories related to the *disruption* phase arose from their injured body and delusional memories that did not make sense to them. In the later phases, after ICU discharge, bad memories resulted from inconsistent information, a feeling of not recognizing oneself, and the perception that life was forever changed.

At the same time, patients had good memories arising from attention received when the injury occurred and the initial care (*vigilance* phase). Good memories also arose from the physical comfort provided by ICU nurses, support by family, and information about the world outside the ICU (*disruption* phase). After ICU discharge, good memories were related to gratitude for life and wanting to win life back again when returning home (*enduring* and *suffering*). In the final stage, *learning to live with the altered self,* patients needed to balance bad memories with good ones in order to get on with life and to be accepting of their situation (Ringdal et al., 2008). This is where diaries and ICU follow-up services can play an important role.

Future Directions

Patients need to know what happened during their ICU stay, to facilitate psychological well-being (Hupcey & Zimmerman, 2000), and for this reason follow-up services play a vital role in the continuum of ICU care. Research shows that, in general, patients are very satisfied with ICU follow-up care (Engstrom, Andersson, & Soderberg, 2008; Glimelius Petersson et al., 2011; Prinjha, Field, & Rowan, 2009; Samuelson & Corrigan, 2009). However, we lack empirical evidence of its beneficial effect on psychological well-being. The largest randomized controlled trial of ICU follow-up clinics conducted to date, comprising structured case review, discussion of ICU experiences, assessment of the need for specialist medical referral, and screening for psychological morbidity, failed to detect an improvement in psychological HRQoL (Cuthbertson et al., 2009). It may be that current tools for measuring psychological HRQoL are insensitive to the subtle changes that occur over time and that further work is required to develop and validate appropriate measures.

Another important question for future research is which patients are most likely to benefit from follow-up services. An ICU length of stay of 3 to 4 days is generally used as an indication for commencing a diary or making a referral to follow-up services. In Sweden, this is stipulated by the SIR. Yet we do not know if this is the best criterion for commencing a diary and prescribing follow-up care. Some patients with shorter ICU stays may experience psychological morbidity but be ineligible for follow-up services, while patients with longer ICU stays may not always need this potentially resource-intensive intervention. Screening of patients' psychological well-being upon ICU discharge may be an alternative. However, no existing psychological measures have been validated for this purpose.

Another aspect of follow-up interventions designed to improve psychological well-being that requires further investigation is the structure and content of clinic visits. We do not know the optimal number, timing, or structure of follow-up visits. There also is a need for discussion about the most cost-effective approach for follow-up services that enable physical, psychological, and social rehabilitation using an individualized approach.

Conclusion

There is substantial evidence that many patients experience stressful, frightening, and delusional memories as a result of their ICU stay and that these memories last for many years. Some patients have impaired psychological health after critical illness, which may be associated with these memories. Diaries and follow-up services are two interventions that can mediate the psychological impact of critical illness. It is useful if follow-up services employ a relevant theory, such as that proposed by Morse (1997), as a framework to situate patient memories. Existing evidence indicates that follow-up services require modest resources and are viewed as valuable by patients and their family members. However, there are still limited data on the impact of follow-up services on psychological well-being in the long term. Promoting quality of life as well as saving lives is now firmly on the ICU agenda. Therefore, we need to continue to investigate interventions that are deliverable both within the ICU and after ICU discharge and that prevent or ameliorate psychological morbidity.

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Résumé

Les facteurs de stress du personnel infirmier qui fournit des soins palliatifs de fin de vie dans les services de soins intensifs

Céline Gélinas, Lise Fillion,
Marie-Anik Robitaille, Manon Truchon

Cette étude avait pour objectif de décrire les facteurs de stress du personnel infirmier qui fournit des soins palliatifs de fin de vie (SPFV) dans des services de soins intensifs (SSI). L'étude a été réalisée selon un plan d'analyse descriptive et qualitative, et 42 infirmières au total provenant de cinq SSI de la province de Québec, au Canada, y ont participé, réparties dans 10 groupes de discussion. Les facteurs de stress ont été regroupés dans trois catégories : organisationnels, professionnels et affectifs. Les principaux facteurs de stress organisationnels mentionnés ont été le manque d'une approche en matière de soins palliatifs, les difficultés interprofessionnelles, l'absence de continuité dans les plans de maintien des fonctions vitales et de traitement, et les demandes contradictoires. Les facteurs de stress professionnels étaient le manque de compétences en SPFV ainsi que la difficulté de communiquer avec les familles et de collaborer avec les autres membres de l'équipe médicale. Les facteurs de stress affectifs décrits comprenaient les conflits de valeurs, le manque de soutien affectif, et la souffrance des patients et de leur famille. Les auteures concluent que la prestation des SPFV est stressante pour le personnel infirmier des SSI et qu'il faudrait élaborer des programmes de formation et de soutien permettant d'assurer la qualité des SPFV dans un environnement de soins intensifs.

Mots clés : facteurs de stress, infirmières, fin de vie, soins palliatifs, services de soins intensifs

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Stressors Experienced by Nurses Providing End-of-Life Palliative Care in the Intensive Care Unit

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The purpose of this study was to describe stressors experienced by nurses in providing end-of-life palliative care (EoL/PC) in intensive care units (ICUs). A descriptive qualitative design was used. A total of 42 nurses from 5 ICUs in the province of Quebec, Canada, participated in 10 focus groups. Stressors were found to be clustered in 3 categories: organizational, professional, and emotional. The major organizational stressors were lack of a palliative care approach, interprofessional difficulty, lack of continuity in life-support and treatment plans, and conflicting demands. Professional stressors included lack of EoL/PC competencies and difficulty communicating with families and collaborating with the medical team. Emotional stressors were described as value conflicts, lack of emotional support, and dealing with patient and family suffering. The authors conclude that providing EoL/PC is stressful for ICU nurses and that education and support programs should be developed to ensure quality EoL/PC in the critical care environment.

Keywords: stressors, nurses, end of life, palliative care, intensive care unit, adults

Introduction

Palliative care is intended to improve the quality of life for both patients experiencing a life-threatening illness or at end of life and their families (World Health Organization, 2002). In Canada, access to specialized palliative care is limited and deaths occur in a wide variety of health-care settings (Canadian Hospice Palliative Care Association, 2008), many in hospital settings. Of the 235,217 deaths in Canada in 2007, 156,685 (66.6%) occurred in hospital, and in the province of Quebec the proportion of deaths taking place in hospital reached 86% (Statistics Canada, 2007, p. 21, table 2.2). Many of these deaths occur in specialized care units, including intensive care units (ICUs). In a Canadian report (Heyland, Lavery, Tranmer, Shortt, & Taylor, 2000), a mean of 18.6% of hospital deaths occurred in specialized care units, mainly ICUs and coronary care units, with a larger proportion of these deaths occurring in teaching hospitals (27%) than in non-teaching hospitals (15%). Given the high incidence of deaths in the ICU, end-of-life palliative care (EoL/PC) in this critical care setting is a major concern. Providing EoL/PC in the ICU may be stressful for nurses as it differs from curative care, which is the primary goal of intensive care medicine. This present study is specific to the ICU context and is a follow-up to the work of Fillion, Saint-Laurent, and Rousseau (2003), which describes the stressors related to palliative care nursing in Quebec.

Background

Workplace stress generally occurs when the demands (also called "stressors") of the work environment exceed the employee's coping resources (Cox, Griffiths, & Rial-Gonzalez, 2000; Fillion et al., 2007). It contributes to negative outcomes at both the organizational and the individual level. At the organizational level, work-related stress tends to be associated with high rates of absenteeism (Brun, Biron, Martel, & Ivers, 2003; Moreau et al., 2004; Verhaeghe, Mak, Van-Maele, Kornitzer, & De-Backer, 2004) and can affect employees' performance and productivity (Beehr, Jex, Stacy, & Murray, 2000). At the individual level, stress experienced at work is understood to be related to a high incidence of health problems (Niedhammer, Tek, Starke, & Siegrist, 2004), burnout (Jourdain & Chênevert, 2010), and job dissatisfaction (Fillion et al., 2007).

It is well documented that nurses perceive several demands or stressors in providing EoL care, and this applies to a wide variety of contexts of care (Holland & Neimeyer, 2005; Hopkinson, Hallett, & Luker, 2005). In a study by Fillion et al. (2003), which was aimed at describing stressors related to palliative care nursing in Quebec, 60 nurses working in various settings (i.e., palliative care units in hospitals, CLSCs [government-run clinics], private palliative care hospices) participated in nine focus groups. ICUs were not included in the study. The authors describe an interesting framework of three categories of stressor experienced by nurses: organizational, professional, and emotional. *Organizational stressors* are demands related to work organization and to the particular environment in which nurses practise. Several difficult working conditions confronted by nurses on a daily basis can generate stress. The main organizational stressors identified by Fillion et al. (2003) are lack of recognition of palliative care as a specialty, lack of structural organization, work overload, ambiguity of roles, lack of human and material resources, lack of involvement in decision-making, and lack of support. *Professional stressors* correspond to demands and expectations related to the nurse's professional role. Lack of collaboration on the medical team (e.g., lack of a treatment plan), difficulty relieving pain and managing symptoms, lack of education and training, lack of time to devote to patients and families, and difficulty maintaining distance within therapeutic relationships were the major professional stressors identified by nurses. *Emotional stressors* are associated with emotional demands and existential issues linked to death and the dying process. Exposure to the suffering of patients and families and exposure to multiple deaths are examples of emotional stressors that can contribute to distress in nurses (Fillion et al., 2003). Value conflicts and conflictual demands associated with providing acute and palliative care simultaneously are also described in this category and are related to emotional stress (Fillion et al., 2003). Emotional stress associated with moral stressors is also referred to as moral distress or ethical suffering (Langlois, Dupuis, Truchon, Marcoux, & Fillion, 2009).

In their literature review, Espinosa et al. (2008) analyze 22 studies (13 quantitative and 9 qualitative) describing the stressors or obstacles experienced by nurses while providing EoL care in the ICU. While most of these studies did not deal with integration of stressors in depth, they enabled the identification of major sources of stress to which ICU nurses are exposed. This first attempt to integrate diverse findings identifies three major organizational stressors: lack of involvement in the planning of care, staffing issues and work overload, and environment. Not surprisingly, nurses stated that they were frequently excluded from discussions regarding a patient's care plan and that they played a limited role in decision-making on withdrawal of life support (Calvin, Kite-Powell, & Hickey, 2007; Halcomb, Daly, Jackson, & Davidson, 2004; Keenan, Mawdsley, Plotin, & Sibbald, 2003; Kirchhoff et al., 2000; Rocker et al., 2005). Work overload was perceived as an obstacle to the provision of quality EoL care and scheduling did not permit continuity of care for patients (Beckstrand & Kirchhoff, 2005). Space limitations in the ICU precluded family access to dying patients, family meetings, and a place to rest (Kirchhoff et al., 2000; Nelson et al., 2006; Rocker et al., 2005).

Professional stressors experienced by ICU nurses included disagreement among physicians and other members of the health-care team, inadequacy of pain relief, unrealistic expectations by families, and lack of experience and education (Espinosa, Young, & Walsh, 2008). For nurses, disagreement among physicians regarding the patient's prognosis was one of the major obstacles (Beckstrand & Kirchhoff, 2005; Calvin et al., 2007; Kirchhoff et al., 2000; Nelson et al., 2006). Such disagreement can lead to the use of extraordinary measures and the prolongation of unnecessary treatment (Calvin et al., 2007; Halcomb et al., 2004; Keenan et al., 2003; Kirchhoff et al., 2000; Puntillo et al., 2001; Robichaux & Clark, 2006; Rocker et al., 2005). Nurses often felt that the patient's pain was not adequately relieved (Puntillo et al., 2001). High expectations from families can also be disruptive and lead to changes in the patient's treatment plan in order to accommodate their needs (Badger, 2005). The time required for nurses to intervene with family members can interfere with patient care (Beckstrand & Kirchhoff, 2005; Calvin et al., 2007; Halcomb et al., 2004; Nelson et al., 2006). Also, family members and friends continually calling the nurse rather than a designated person for an update is highly disruptive (Beckstrand & Kirchhoff, 2005; Crump, Schaffer, & Schulte, 2010). In addition, nurses have expressed a need for more education in EoL care (Desbiens & Fillion, 2011; Fillion, Fortier, & Goupil, 2005; Nelson et al., 2006; Rocker et al., 2005).

Difficulty coping has been reported as the main emotional stressor for ICU nurses (Espinosa et al., 2008). Accompanying the patient and the family in the dying process can cause suffering and moral distress in nurses (Elpern, Covert, & Kleinpell, 2005; Jezuit, 2000). In one study (Puntillo et al., 2001), only 13% of 906 ICU nurses reported that they had access to support. The presence of high moral distress and the absence of support can contribute to burnout in nurses (Holland & Neimeyer, 2005; Meltzer & Huckabay, 2004).

In a recent descriptive phenomenological study (Espinosa, Young, Symes, Haile, & Walsh, 2010), 18 ICU nurses at a US teaching hospital participated in individual interviews and focus groups. The findings supported stressors identified in the integrative review (Espinosa et al., 2008) but also identified other sources of stress. In the category of professional stressors, nurses described concerns related to the medication dosages necessary to keep the patient comfortable, which can potentially cause respiratory depression. Two additional emotional stressors were described: a feeling of abandonment and powerlessness, and difficulty caring for younger patients. Nurses spend most of their time with the patient, yet have to cease treatment and withdraw tubes as per the physician's orders. Therefore, they often feel abandoned and responsible for patients as they die. Also, they experience feelings of powerlessness and failure when the patient does not get well. The situation is particularly difficult for nurses providing EoL care to younger patients, as it makes them realize that mortality can touch their own lives (Espinosa et al., 2010). That study was limited to a single setting in the United States and its findings cannot be transferred to the Canadian context. Transferability would require the inclusion of different settings, as in the approach by Fillion et al. (2003).

Purpose

This study was aimed at better understanding the stressors experienced by nurses providing EoL/PC in Canadian ICUs. The objective was to describe the stressors related to the provision of EoL/PC in the ICU from the perspective of nurses in different settings in the province of Quebec.

Methods

Design

A descriptive qualitative design was used for the study.

Sample

The sample comprised different groups of nurses working in various ICU settings. Settings were selected to be representative of the variety of hospitals in Quebec in terms of location (urban or rural), organization (presence or absence of intensivists and of a palliative care team), and status (teaching or non-teaching). A total of five French-speaking and English-speaking ICUs in three regions of the province were selected. In each setting, an intentional sample of bedside ICU nurses from all work shifts (day, evening, and night) was recruited.

Procedure

With the support of the nurse managers, the study was orally presented to ICU nurses by the research coordinator, and nurses who were interested in participating gave their names. Two focus groups were scheduled in each setting, for a total of 10 focus groups. The sessions were co-facilitated by a researcher and the research coordinator, were 40 to 60 minutes in duration, and were audiorecorded. The focus groups were held in non-threatening environments (i.e., rest areas or conference rooms) and the facilitators were respectful of the diversity of opinions (Krueger, 2006). Saturation of data was achieved, as no new information emerged at the completion of the focus groups. The study received ethical approval at each site.

Figure 1 ***Questions Included in the Discussion Guide***

Themes	**Questions**
Description of sources of stress (stressors)	Based on your role as an ICU nurse, tell us about the sources of the stress (barriers or obstacles) you experience when providing EoL/PC to your patients?
Factors associated with the production of these stressors	In your opinion, what factors contribute to the stress you experience when providing EoL/PC in the ICU? What makes you feel uncomfortable or dissatisfied when providing EoL/PC to a patient?

Table 1 *ICU Settings and Participants*

Site	Urban or Rural	Teaching or Non-teaching Hospital	Open or Closed ICU	Palliative Care Resources	Gender		Mean Age	Age *(SD)*	Education			Years' Experience	
					Male	Female			Diploma	BSc	MSc	ICU	Total
A	Urban	Teaching	Semi-closed	Yes	1	6	37.4	12.1	4	3	0	10.7	14.9
B	Urban	Teaching	Closed	No	0	6	43.0[a]	12.3	5	0	1	14.1	21.0
C	Rural	Non-teaching	Open	No	0	9	36.2	5.9	4	5	0	10.6	13.0
D	Urban	Teaching	Closed	Yes	0	12	44.9[a]	8.5	4	8	0	14.0	20.0[a]
E	Urban	Teaching	Closed	Yes	1	7	35.0	6.5	5	2	1	6.6	8.06

[a] Missing data

Instruments

The discussion guide developed by Fillion et al. (2003) was adapted to the ICU context and included two themes: identification and description of stressors experienced in providing EoL/PC in the ICU, and process or causative factors associated with the production of these stressors in the ICU context. Specific questions are provided in Figure 1.

Data Analysis

The audiorecordings for all focus groups were integrally transcribed and reviewed. The three categories of stressor (organizational, professional, and emotional) as described by Fillion et al. (2003) were used as a foundation for developing a categorization scheme. Using the NVivo7® program, we created descriptive codes by attributing a code to each unit of analysis (words, phrases, or paragraphs) highlighting an issue. Content analysis followed the approach of Miles and Huberman (1991). The merging of similar descriptive codes created thematic categories representing a set of conceptual components (stressors). To ensure rigour, we addressed transferability, credibility, and plausibility (Murphy, Dingwall, Greatbatch, Parker, & Watson, 1998). The diversity of the sites served to enhance transferability, while double codification by two members of the research team served to enhance credibility. Respondent validation was performed with ICU nurses in two of the settings. Finally, to enhance plausibility, stressor classification and their related verbatim dialogue were discussed by the team in order to reach consensus.

Results

Settings and Sample

Except for one rural, non-teaching site, all sites were both urban and teaching. Three settings had full-time intensivists in charge of the ICU (what is called a "closed ICU"), one site had intensivists only during the week (semi-closed ICU), and one site had non-intensivists in charge of ICU patients (open ICU). Three sites had palliative care teams covering the ICU, one site had one physician specialized in palliative care, and one site had no palliative care resources at all. A detailed description of each setting is provided in Table 1.

The sample comprised 42 bedside ICU nurses (Table 1). Most participants were female and their mean age was 35.4 years. Two participants held a master's degree in nursing; the others held either a nursing diploma (*n* = 22; 52%) or a bachelor's degree in nursing (*n* = 18; 43%). The mean number of years working as a nurse was 15.0, including 11.3 years working in the ICU.

Table 2 ***Organizational, Professional, and Emotional Stressors***

Organizational	**Professional**	**Emotional**
Lack of a palliative care approach – *environmental resources* – *human resources*	Lack of EoL/PC competencies	Value conflicts
Interprofessional difficulty	Difficulty communicating with families; complaints	Lack of emotional support
Lack of continuity in life-support and treatment/care plans Conflicting demands	Difficulty collaborating with medical team on EoL/PC issues – *lack of involvement of nurses in life-support and treatment planning* – *lack of medical leadership in EoL/PC decision-making* – *lack of EoL/PC protocols*	Dealing with patient and family suffering

Stressors

A list of stressors was identified for each of the three categories: organizational, professional, and emotional. All stressors described were addressed in half or more of the focus groups. A list of the identified stressors is provided in Table 2.

Organizational stressors. According to this three-category approach, organizational stressors correspond to the demands related to work organization and to the particular environment in which nurses practise (Fillion et al., 2003). Four major organizational stressors were identified: lack of a palliative care approach, interprofessional difficulties, lack of continuity in life support and treatment plans (level of care), and conflictual demands.

Lack of a palliative care approach. The main issue highlighted by nurses was the omission of EoL/PC in the structural organization and culture of the ICU. Indeed, the ICU was considered mainly as an aggressive curative care environment in which EoL/PC did not appear to fit:

> *In the ICU we save people. We're not at end of life in the ICU. There isn't this mentality. That's not . . . the population . . . In the ICU there are chances that they will survive, absolutely.* (free translation[1])

This lack of a palliative care approach appeared to be reflected in two main organizational aspects: environment and material resources and human resources.

Environment and material resources. The major stressor highlighted by nurses in all focus groups was the ICU environment. The technology surrounding the patient's bed (e.g., monitors) and the noise from monitor alarms made the ICU a stressful environment in which to die:

> *An ICU room is not the ideal place to die. There's a monitor, a team . . . a respirator, pumps . . . We try to remove some [of the equipment] to make it as nice as possible, but the fact remains that it's not a nice unit . . . with a view of the river or a garden.* (FT)

Some ICUs had a limited number of closed rooms and intimacy was difficult to achieve. Also, rooms in the ICU could be so small that it was challenging to make space for the family to be at the bedside. Spaces reserved for families were limited or non-existent. The shortage of ICU beds created additional pressure:

> *I had a family who were waiting for a brother coming from elsewhere to pull the plug. We were waiting, but I still had the operating room: "hurry, hurry, hurry" . . . And it turned out that the sister, the patient's daughter,*

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[1] Hereafter, the abbreviation FT will be used to indicate "free translation."

> *heard this. And then she said to us, "Well, I mean, if we have to pull the plug we won't wait for him" . . . I still get the shivers . . . So I said, "We're talking about your father here, you are the priority" . . . but I thought it was . . . I can't even find the word for it . . . well, it was inhuman.* (FT)

Human resources. In addition to the shortage of specialized ICU nurses, especially on weekends or on the evening or night shift, limited availability of health professionals such as mental health or spiritual care providers was described as a barrier to EoL/PC in the ICU:

> *We get stuck if such a situation happens in the evening. Stuff happens at night, you got to deal with it by yourself. They have a social worker for these situations, but then basically everything stops at 4 o'clock . . . from 4 o'clock [on] from Monday to Friday [and] on the weekend you're totally, totally without support — you have nobody.*

Interprofessional difficulties. According to all the nurses, interprofessional collaboration and efficient ways to exchange information were key elements in achieving coherent care and treatment plans and ensuring continuity of communication between health-care team members and families:

> *The doctors disagree with each other, too, which is why decisions get changed, but, you know, it needs to be communicated with the nurse why we're changing this . . . why we're changing the decision this week because this doctor feels there's this hope or this other test that can be done, at least so we know how to communicate that to the family and we're all on the same . . . level.*

Nurses reported that, too often, information about changes in care plans, life support and treatment plans was neither noted in the medical file nor communicated to the nurse in charge. Such situations put the nurses in an uncomfortable position:

> *Sometimes they don't even have time to put us up to date with the changes in their own plan, so then sometimes we don't even know what they change . . . sometimes we have to ask the patient, the family members . . . sometimes the family members know more than I do.*

Interestingly, some nurses stated that they did not often consult with the palliative care team of the hospital and could not clearly explain why. For them, it was still new to have this team in the ICU, while it was more common in the case of oncology patients.

Lack of continuity in life support and treatment plans. Many nurses described problems reaching consensus on decision-making surrounding the curative/palliative care transition and on medical decisions concerning level of care. While some physicians decided to maintain an intensive level of care, others prescribed comfort care for the same patient. Therefore, the plan of care/treatment changed with the rotation of physicians and created difficult conditions for the nurses, the patient, and the family:

> *Then 1 week later . . . [the] doctor changes and then they change the plan, which then gets the family even more confused because one doctor has one idea and then the other doctor has another idea.*

> *For me, stress is caused by the absence of consensus. We have patients who one day are at level 2 and the next day at level 1 . . . we know they're alive but there can be no medical consensus. It can be a stressor, because one day they can be level 2 and the next day level 1, so we start over. There's no medical consensus on how to define a patient as being at end of life. The level of care required is often very ambiguous from one doctor to another . . . it's the perfect stressful element.* (FT)

Conflictual demands related to providing curative and palliative care simultaneously with different patients were described as a source of stress by most nurses. Nurses could be assigned to a patient with a chance of survival as well as a dying patient. The participants believed that, in such situations, they had to give priority to the patient who might survive and to dedicate most of their time to providing technological care with effectiveness and speed. Too often, there was no time left for palliative care:

> *Sometimes I see them . . . looking [sigh] and they're alone. . . . You wish you could spend that time with them . . . like, sit with them . . . sometimes family is not there and you should be there . . . so a person doesn't die by himself/herself, and, well . . . they're not, and the person dies alone. . . . For me that's a big thing, for someone to die alone . . . you can't be there, like, to sit 2 minutes and hold a person's hand if they're scared or — "I'm sorry, my alarms are beeping across" [in the other room].*

Professional stressors included demands and expectations related to the nurse's professional role (Fillion et al., 2003). Three main professional stressors were described: lack of competency in EoL/PC and in the palliative care approach, difficulty communicating with families and dealing with complaints, and difficulty collaborating with the medical team around EoL/PC issues.

Lack of competency in EoL/PC and in the palliative care approach. All nurses mentioned their lack of competency in providing EoL/PC care, including the assessment and management of symptoms, and lack of competency in the palliative care approach, including the social, emotional, spiritual, and practical domains.

> *To have better tools . . . when I look [around] I get the impression that there are symptoms associated with death that maybe we're not familiar with. . . . The pain . . . the stress associated with it — do we have the tools for this? Whether the patient is conscious or not — sometimes they're completely conscious until the end. Are we doing what we should? . . . sometimes I'm not sure, and that can be stressful.* (FT)

> *When a lot of people ask about funeral arrangements and things like that, we get lost as to what to say . . . so maybe to have that reference, someone to sit with the family and talk about those things and help them make arrangements. It's a very stressful thing to do when someone dies.*

Nurses deplored having to learn EoL/PC on the job and having to support the residents and fellows as well as new, young ICU nurses.

Difficulty communicating with families and dealing with complaints. All the nurses discussed experiencing difficulty communicating with families. Because nurses are more present at the bedside of the patient than physicians, families regularly query them about different aspects of the patient's condition and about the care and treatment plans. Nurses said that they felt uncomfortable not being able to communicate information to the family:

> *I think it's frustrating when you can't be authentic with the family. You know that this patient is going to die and the family will ask you how they're doing, [if] they're doing better, and . . . you can't be honest with them. So there's a sense that you can't be authentic, you can't be real with the family. . . . everybody else is in denial and won't bridge that . . . reality with the family, so you have to continue to perpetuate it.*

In addition, families may have difficulty understanding the information provided by the physician and will turn to the nurses for explanation. This situation added to the stress of having to be the bridge between the family and the physician. As a consequence of these communication difficulties, nurses sometimes received complaints from one or another of the parties. In half of the focus groups, nurses said that they found it stressful to receive critical comments from the family or the physician:

> *We've received complaints that we've poorly managed end of life . . . The entire unit is affected . . . you have the impression that you've done a lot and the family thanks you at the time, but afterwards you receive a complaint. That makes it difficult. . . . It puts your own work into question.* (FT)

Difficulty collaborating with the medical team around EoL/PC issues. The nurses described three stressors related to their collaboration on the medical team: lack of involvement of nurses in life-support and treatment plans, lack of medical leadership in EoL/PC decision-making, and lack of EoL/PC protocols.

Lack of involvement of nurses in life-support and treatment plans. While nurses are the medical professionals most present at the bedside and have a privileged relationship with the patient and family, many nurses explained that they were not involved in the planning of care as part of the medical team:

> *It ended up that both times the doctor didn't include me in the meeting with the family to find out what had been going on, what had been said, how they felt about it. So all of a sudden the family arrived with the doctor, at the bedside, and he told me, "Okay, unplug everything." . . . the family members were there and they were looking at me.* (FT)

Lack of medical leadership in EoL/PC decision-making. Similarly, some nurses pointed to the neglected role of the physician in guiding families in the decision whether to withdraw life support. They deplored the absence of open discussion around EoL/PC issues that were not under nurses' control and that had to be initiated by the patient or the physician:

> *There are families who are unable to make the decision . . . to end a life, so the doctors should take on that role more. They are the ones with the medical experience, not the families. The families don't feel comfortable making the decision because they don't possess the knowledge.* (FT)

Lack of EoL/PC protocols. The lack of EoL/PC protocols can lead to discomfort for the patient and difficulty controlling symptoms. Most nurses mentioned how hard it was to obtain prescriptions to adequately relieve symptoms, including pain. Having access to a predetermined care protocol would accelerate and facilitate the process for both the nurse and the patient:

> *Protocols. . . directions . . . [so that] it's not left to the individual nurse or even the resident or staff person to have to anguish over decisions that have been made, because it's about the things that you should be doing for a patient who's dying. . . . They don't have to make the call, they don't have to feel guilty that, oh, you know, I should have done this or I should have done that. No, this is what we'll be doing.*

Emotional stressors are emotional demands and existential issues linked to EoL care and the palliative care approach (Fillion et al., 2003; Vachon, Fillion, & Achille, 2009). Three emotional stressors were addressed: value conflicts, lack of emotional support, and dealing with patient and family suffering.

Value conflicts. All the nurses described being uncomfortable with unnecessary life-support and treatment measures. Nurses expressed discomfort not only with treatment plans but also having to go against their own values:

> *There's another conflict that nurses are not too comfortable [with], like, you think that the patient should be on comfort measures but the doctors are still going on and on with all these treatments . . . so there's a conflict with the doctors and nurses taking care of the patient.*

They found it very frustrating that once all treatments were completed and there was no hope for life, little space was made for EoL/PC:

> *It infuriates me when I persist for 2 to 3 weeks with a patient with highly technological care using incredible techniques . . . and [then] we just give up and say, "Well, now we're done," and we give no importance to that aspect of end of life. I'd like to be able to give as much attention to the time they [patient and family] will be spending together. I'd like to be able to do that. I'd say, look, mission accomplished, I succeeded.* (FT)

Similarly, dealing with conflicting demands associated with providing curative and palliative care simultaneously, described earlier as an organizational stressor, became a source of ethical suffering. Many nurses expressed dissatisfaction with their work because they were unable to provide optimal care. They felt that they were rushed and could not do their best for the dying patient and the family:

> *It's disappointing for us, . . . we're not able to give our maximum because, you know, if we have two patients and one of them requires more care, we'll go to them . . . while the other will die . . . we don't get any satisfaction.* (FT)

Lack of emotional support. Most nurses also felt that they were not given emotional support when they needed to express their feelings, and it was difficult as well for them to find this support outside of work:

> *We go through a lot during the week, not just death but huge traumas — young people — and you go home and talk to people who don't want to hear [about] it: "Could you change [the] subject?" . . . "It's depressing." "Do you have to talk about this over dinner?" . . . we see a side of life . . . that most people don't see.*

This *lack of emotional support* could make nurses less available to patients' families and place them at risk for coping problems and intense suffering: "Sometimes I cry once I get home, from being so exhausted." (FT)

Dealing with patient and family suffering. It appeared that supporting patients' families had not been taken into account in the planning of care. Most of the nurses were often left to handle the family's needs and the patient's care by themselves: "We want to take care of the patient but there's also the family who demand a lot [of attention]." (FT)

Many nurses said they found it difficult to be exposed to suffering by the patient and the family. Being the ones to disconnect the patient from the machines was stressful and represented a weighty medical task. Also, nurses had the feeling that the families associated their actions with the death of the patient:

> *That burden, of the family standing around, looking at you and saying, "Hey, he's pulling the plug," and . . . you arrive with your syringe to relieve the pain. Well, if the patient dies 10 minutes later . . . what's noticed, that you relieved their pain or that you made them die? Well, unfortunately, what they remember is that you made them die. . . . all those last moments, they've permeated [their brains].* (FT)

Discussion

Stressors experienced by nurses working in the ICU were similar to those described by nurses working in palliative care in hospitals and in the community (Fillion et al., 2003) and to those described in the review by Espinosa et al. (2008). Many stressors were identified in the three categories established by Fillion et al. (2003): organizational, professional, and emotional. Consistent with the findings of Fillion et al. (2003), while stressors identified in each category seemed to be interrelated, the nurses reported mostly organizational stressors. The most demanding issue appeared to be *not* having to deal with death, dying, and suffering, but, rather, having to fight to ensure decent conditions for the patient.

From an organizational perspective, the main stressor — which contributed in turn to other sources of stress — appeared to be the absence of a palliative care approach or the failure to consider EoL/PC as part of the ICU culture, and the related difficulty with decision-making and the planning of care. This finding is consistent with the results of an ethnographic study on ICU culture by Baggs et al. (2007). EoL/PC in this critical care context should be seen as a natural step and should be better integrated into the care plan for the patient and family. The interprofessional difficulty reported was mainly the result of disagreement between physicians on the directives for treatment (Beckstrand & Kirchhoff, 2005; Espinosa et al., 2010) and breakdown in communications between physicians and nurses. In both cases, the absence of open discussion around

EoL/PC issues between physicians and patients/families seemed to be a source of stress for the nurses. This is also reflected in several comments about difficulty communicating with families and physicians included in the category of professional stressors. Clinical guidelines for the palliative care approach clearly advise that end-of-life issues be addressed directly (Clayton, Hancock, Butow, Tattersall, & Currow, 2007; Truog et al., 2008). When a discussion is opened, a broad range of palliative care services may be offered, including symptom management, advance care planning, psychological and spiritual support, transition of care, and referral to a palliative care unit or a palliative care team (Clayton et al., 2007; Truog et al., 2008). Documentation on how and which of these services can be emphasized in the ICU setting is clearly needed.

Conflictual demands associated with the mixed approach of providing both curative and palliative care, while not new, do warrant more attention (Beckstrand & Kirchhoff, 2005; Fillion et al., 2003; Fillion, Desbiens, Truchon, Dallaire, & Roch, 2011). This mixed approach becomes an issue when professional activities are not well defined. Taking care of a dying patient and his/her family is demanding and time-consuming work. This does not seem to be taken into account in the assignment of ICU nurses. Also, as the ICU is considered mainly a curative care environment, nurses give priority to patients who have a chance of survival and feel that they are abandoning the dying patient — thereby adding to emotional stressors and causing ethical suffering. Time constraints and other stressful factors characteristic of the mixed approach have also been described for home care practice (Burt, Shipman, Addington-Hall, & White, 2008) and oncology settings (Campos de Carvalho, Muller, Bachion de Carvalho, & de Souza Melo, 2005). The ability to provide EoL care in different settings, including the ICU, has advantages, such as facilitating access to EoL care for patients and families. But it also has stressful effects that need to be addressed at an organizational level. Adapting, implementing, and evaluating a palliative care approach and services tailored to the critical care setting constitute an interesting area for future work.

Professional stressors are related mainly to inadequate education and supervision in EoL/PC, as is largely acknowledged by ICU nurses (Espinosa et al., 2010; Nelson et al., 2006; Rocker et al., 2005). As the ICU is seen primarily as an aggressive curative care environment, nurses are not well trained to provide EoL/PC, although they may develop competencies with exposure to death over time. As dying is a reality in the ICU, there is a clear need for nurses and other members of the medical team to be trained in EoL/PC. The availability of EoL/PC education and training programs would increase their knowledge and their competencies in planning and delivering EoL/PC (Efstathiou & Clifford, 2011). Such an educational strategy would also address other stressors described by ICU nurses, including difficulty in assessing and managing pain and other symptoms and in communicating effectively with families as a health-care team (Beckstrand, Callister, & Kirchhoff, 2006; Espinosa et al., 2010). Communication problems were another stress factor described by the nurses — for example, complaints by a family or a physician could add to their suffering and moral distress. Such situations ought to be taken seriously and managed, with the support of the nurse manager and the nursing administration.

Emotional stressors can be seen as a consequence of the other two categories of stressor. Indeed, it is not surprising that the ICU nurses were exposed to value conflicts related to aggressive curative treatments being offered until the end, when they were considered unnecessary (Espinosa et al., 2008, 2010). Promoting earlier cessation of treatments or not initiating aggressive treatments when they are expected to be futile would minimize this moral conflict (Beckstrand et al., 2006), which could lead to ethical dilemmas and ethical suffering (Langlois et al., 2009). Also, their role as the health-care professional who stops treatment and withdraws tubes makes ICU nurses feel abandoned and powerless while carrying a weighty medical burden (Espinosa et al., 2010). An intervention has recently been developed to facilitate interdisciplinary decision-making and thus improve the decision-making process and prevent ethical suffering (Bolly, 2011). Similarly, to ease discomfort surrounding decisions on levels of care, the provision of advanced life-support necessitates explicit decision-making about how life-support measures should be used (Cook et al., 2006).

Implications for Nursing

Our findings suggest that stressors related to the provision of EoL/PC in the ICU are numerous, are similar to those found in other contexts of care, and exist internationally. Recommendations to improve EoL/PC in the ICU have recently been published by the American College of Critical Care Medicine (Truog et al., 2008). These include development of the competencies of ICU clinicians in providing this type of care, improved communication with families, and bereavement programs for families or for health professionals/clinicians. Given our findings and these recommendations, it is urgent that education and support programs be developed in collaboration with nurses and other members of the health-care team to improve the quality of Eol/PC in the ICU.

Conclusion

Providing EoL/PC is stressful for ICU nurses in Quebec. The numerous stressors to which ICU nurses are exposed can contribute to their own suffering and distress. Research is needed to develop, implement, and evaluate programs in order to better support ICU nurses in providing EoL/PC. We need documentation on the impact of such programs on nurses' well-being and job satisfaction as well as on organizational outcomes and clinical outcomes for patients and families.

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Résumé

L'optimisation des soins de fin de vie dans les unités d'enseignement clinique de médecine à l'aide du questionnaire CANHELP et d'une infirmière facilitatrice : une étude de faisabilité

Christopher Frank, Melissa Touw, Jeannette Suurdt, Xuran Jiang, Phil Wattam, Daren K. Heyland

Cette étude a pour objectif d'effectuer un essai-pilote et d'évaluer l'effet et la faisabilité d'une intervention en amélioration de la qualité dirigée par une infirmière facilitatrice utilisant le questionnaire du projet d'évaluation de la santé au Canada (CANHELP) pour améliorer les soins de fin de vie (FV) dans les unités d'enseignement de la médecine. Sur les 123 patients auxquels on s'est adressé, 67 ont accepté de participer à l'étude et la majorité d'entre eux avait le cancer. Le questionnaire a été rempli par des malades en phase terminale et les soignants membres de leur famille. Les chercheurs ont déterminé les aspects des soins présentant l'écart le plus grand entre la satisfaction et l'importance, et les ont ciblés dans la perspective de l'optimisation des soins de FV. Dans une seconde cohorte, ils ont également procédé au dépistage des symptômes à l'aide de l'Edmonton Symptom Assessment Scale (ESAS). Les chercheurs ont évalué les résultats deux semaines après que les patients des deux cohortes ont obtenu leur congé. La satisfaction moyenne à l'égard des aspects prioritaires s'était améliorée. La satisfaction des soignants s'était aussi grandement améliorée ainsi que les résultats de l'ESAS. Grâce au questionnaire CANHELP, l'infirmière facilitatrice a pu repérer des occasions d'améliorer les soins de FV prodigués aux patients dans les unités de médecine et d'améliorer un peu la satisfaction à l'égard des soins.

Mots clés : fin de vie, dépistage des symptômes, questionnaire CANHELP

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Optimizing End-of-Life Care on Medical Clinical Teaching Units Using the CANHELP Questionnaire and a Nurse Facilitator: A Feasibility Study

Christopher Frank, Melissa Touw, Jeannette Suurdt,
Xuran Jiang, Phil Wattam, Daren K. Heyland

The purpose of this study was to pilot-test and evaluate the impact and feasibility of a nurse facilitator-led quality-improvement intervention using the Canadian Health Evaluation Project (CANHELP) questionnaire to improve end-of-life (EoL) care on medical teaching units. Of 123 patients approached, 67 consented to participate. The majority had cancer. The questionnaire was completed by patients with end-stage diseases and their family caregivers. The researchers identified care issues showing the widest gap between satisfaction and importance and targeted these in order to optimize EoL care. In a second cohort, they also screened for symptoms using the Edmonton Symptom Assessment Scale (ESAS). In both cohorts, they evaluated outcomes 2 weeks post-discharge. The average satisfaction of priority items improved. Also, caregiver satisfaction improved significantly and ESAS scores improved. Using CANHELP, the nurse facilitator was able to identify opportunities for improving EoL care in patients on medical units and for making small improvements in satisfaction with care.

Keywords: end of life, hospital care, nursing role, symptom screening, palliative care, The Canadian Health Care Evaluation Project (CANHELP) Questionnaire

Background

It is often said that every system is perfectly designed to get the results that it gets! Canadian research has had poor satisfaction with end-of-life (EoL) care in the hospital setting, which suggests that the health-care system needs to be changed to better meet the needs of people with advanced chronic illness (Heyland et al., 2005). Change initiatives should be informed by the experiences, unmet needs, hopes, and expectations of patients and their families. However, efforts to improve care, particularly at EoL, are often hampered by inadequate definitions of quality and sub-optimal measurement tools (Brown University Centre for Gerontology and Health Care Research, 2004; Lo, 1995; Mularski et al., 2007).

We recently validated a novel questionnaire to measure the quality of EoL care, the Canadian Health Care Evaluation Project (CANHELP) questionnaire, developed expressly for patients with advanced chronic illness, both cancer and non-cancer (Heyland et al., 2010b). To determine high-priority areas for improvement in this population, we interviewed more than five hundred seriously ill hospitalized elderly patients and their families. We asked them what was important to them in terms of care at EoL and how satisfied they were with the quality of their care. By juxtaposing importance and satisfaction ratings, we developed a prioritized quality-improvement agenda. We chose to focus on those aspects of EoL care that were considered important by respondents but were the least satisfactory to them. Priority areas for improvement that we identified from the overall perspectives of patient groups related to a feeling of peace; assessment and treatment of emotional problems; physician availability; and satisfaction that the physician took a personal interest in them, communicated clearly and consistently, and listened (Heyland et al., 2010a). Similar priorities were identified from the perspectives of family members. Additional family priorities included timely information about the patient's condition and discussions with the doctor regarding final location of care and use of EoL technology. This approach can also be used to identify care priorities in an individual patient.

We developed a nurse role to administer individualized CANHELP questionnaires and to link patient responses to the clinical team. This role was adapted from several existing nursing roles intended to improve care for hospitalized patients. A Canadian qualitative study of nurses' perceptions of barriers to good EoL care on admission to acute-care hospitals found that frontline nurses are "being pulled in many directions" but that an important nursing skill for optimizing care is "creating a haven for safe passage," through advocacy, support, and striving for an optimal care environment (Thompson, McClement, & Daeninck, 2006). The importance of nursing advocacy in EoL care is discussed in the literature (Adams, Bailey, Anderson, & Docherty, 2011; Canadian Nurses Association, 2012; Thacker, 2008).

Nursing plays a key role in EoL care in hospital. The nurse navigator in cancer care helps to guide patients through the health-care system and to optimize care and adherence to treatments. The role has been shown to improve adherence to oncology follow-up, but the impact of this approach on symptom outcomes has been variable (Wells et al., 2008). Oncology inpatients who had been seen by an oncology nurse navigator to guide their course of care and their interactions with health-care providers rated their distress as lower compared with usual care (Swanson & Koch, 2010).

Nurses assume the role of "key worker" in the provision of palliative care. This model uses an expert working with a multidisciplinary team, coordinating physical and psychosocial care, and assisting with transitions across health sectors (Committee on Palliative and End-of-Life Care for Children and Their Families, 2003). A more "traditional" nursing role is that of advance practice nurse working within a consultation model to advise on care concerns.

In addition to using the CANHELP questionnaire, we wanted to explore the role of systematic symptom screening in patients with advanced chronic illness in the acute-care setting and to determine whether this screening augmented the information provided by the CANHELP to the medical team. Systematic symptom screening has been studied in palliative cancer patients and has been shown to increase the identification of significant symptoms compared to patient reports provided during an interview (Homsi et al., 2006). However, patients do not always view systematic screening positively. In one study they found the screening questions intrusive and were unclear about the purpose of the screening (McGrath et al., 2005). The Edmonton Symptom Assessment Scale (ESAS) is a validated tool that has been used to measure symptom burden and distress in patients with cancer and heart failure (Bruera, Kuehn, Miller, Selmser, & Macmillan, 1991; Sigurdardottir & Haugen, 2008). To our knowledge, there are no published studies of systematic symptom screening in a population at high risk of dying in hospital on an acute-care general medical unit.

The purpose of this study was to pilot-test and evaluate the impact and feasibility of a nursing-led quality improvement intervention using the CANHELP questionnaire with or without systematic symptom screening, to identify clinical areas for improvement in care for patients with a high risk of death admitted to acute-care medical units.

Methods

The study was a single-centre pilot of a quality-improvement intervention administered on clinical teaching units at the Kingston General Hospital in Kingston, Ontario. There were two sequential cohorts of patients, the first using the CANHELP only and the second using the CANHELP with the ESAS.

Setting

At the time of the project (November 2008–June 2009), the Kingston General Hospital had four internal medicine clinical teaching units (CTUs), each caring for up to 40 patients. The medical staff consisted of attending physician, senior resident in internal medicine, and junior house staff from internal medicine or other disciplines. There was an advance practice nurse affiliated with the CTU patients but there were no nursing roles related to EoL care. The Kingston General is a 438-bed tertiary care teaching hospital. The research nurse (referred to as "nurse facilitator") was not linked formally to any of the CTU teams but saw patients from each team as indicated.

Patient Population

Patients who met the following criteria were eligible for both phases of the study:

(1) 55 years or older

(2) one or more of the following medical diagnoses:
  - *severe chronic obstructive lung disease (COPD)*
  - *severe congestive heart failure*
  - *advanced cirrhosis*
  - *cancer* — metastatic cancer or stage IV lymphoma
  - *end-stage dementia* (inability to perform all ADLs, mutism or minimal verbal output secondary to dementia, bed-bound state prior to acute illness) (For these participants, assessment would be done through the caregiver or the family.)
  - OR *over 80 years of age and frail* — Canadian Study of Health and Aging Clinical Frailty Scale rating of 6 (moderately frail) or 7 (severely frail) (Rockwood et al., 2005)

(3) estimated hospital stay of at least 5 days, to allow time for medical stabilization and for interventions identified on the CANHELP questionnaire

These criteria defined a group of patients with end-stage disease associated with a 50% probability of survival at 6 months based on previous research (The SUPPORT Investigators, 1995). Patients who did not speak English were excluded.

Eligible patients admitted to the Kingston General were identified to the nurse facilitator by the attending physician, medical residents, and other health-care staff. In addition, the nurse reviewed the charts of all new admissions to identify possible participants, particularly after days when patients were admitted to the service through the emergency department.

Participants were asked to identify, if applicable, a family caregiver, defined as the family member/significant other/close friend who "provides the most care to the patient and is not paid to do so." Those individuals identified as family caregivers were approached for recruitment as well.

The Canadian Health Care Evaluation Project (CANHELP) Questionnaire

The details of our initial development of the CANHELP questionnaire have been published elsewhere (Heyland et al., 2006, 2010b). We have demonstrated that the CANHELP questionnaire correlates, as expected, with other established measures at EoL (construct validity), has good internal consistency (Cronbach's alpha > 0.70), and can be grouped into valid subscales (Heyland et al., 2010b). We have developed one version for the patient and two versions for the family caregiver (one if the patient is alive, the other if the patient has died). The patient version contains 37 items in the following subscales: Relationship With Doctors (4 items), Illness Management (14 items), Communication (5 items), Decision-Making (4 items), Role of the Family (6 items), and Your Well-Being (4 items). In the family questionnaires, the factors are Relationship With Doctors (4 items), Characteristics of Doctors and Nurses (5 items), Illness Management (10 items), Communication and Decision-Making (6 items), Your Involvement (7 items), and Your Well-Being (6 items). (The current questionnaire is available at www.thecarenet.ca.)

Intervention

The nurse facilitator was trained in the use of the CANHELP questionnaire and administered it face-to-face with participants or family members. This was done the second day after admission to allow for stabilization of the acute phase of the illness and sufficient time for care issues or concerns to be identifiable by patients or family members.

Two cohorts were sequentially assessed using the CANHELP, the first using the CANHELP alone and the second using the ESAS as well. The Charlson Comorbidity Index and the Palliative Performance Score (PPS) were used to assess the status of all identified patients. The PPS is a validated tool for assessing function and prognosis indirectly in people with cancer (Anderson, Downing, Hill, Casorso, & Lerch, 1996). It has been shown to reflect functional status and to relate also to prognosis of people with a non-cancer diagnosis (Harrold et al., 2005).

We used a computerized algorithm to identify the items with the largest gap between the participant's satisfaction and level of importance. We then provided a hard copy of a report that ordered or ranked the care issues with the largest gaps at the top; we identified these as "improvement opportunities." The nurse facilitator attempted to collaborate with the health-care team by informing them of the top 10 opportunities identified and working on strategies to assess these. Interactions with members of the medical team on the CTU were done via face-to-face contact and through the use of a standardized form to show areas of importance and areas of current satisfaction or dissatisfaction with care and to offer practical suggestions for improving each of the care concerns (see Appendix 1 for a sample of this form). Care issues were raised at multidisciplinary team rounds and identified in chart progress notes. In cases of urgent or severe symptoms, medical house staff were contacted directly. Management of these symptoms followed usual hospital practice. The nurse worked with house staff to identify patients for whom palliative care and/or social work consultation was appropriate based on the unmet needs identified in the CANHELP questionnaire.

First Cohort

The CANHELP questionnaire was administered by the nurse facilitator to a convenience sample of 33 enrolled patients and available family caregivers to assess ratings of importance and current level of satisfaction with different aspects of EoL care.

Second cohort

Based on the same inclusion criteria, a subsequent cohort of 34 patients was identified. In this phase, however, patient symptoms were also assessed using the ESAS, completed by the patient or, if the patient was unable to do so, by the nurse (Bruera et al., 1991). The ESAS scores were used to identify symptom concerns for medical staff and to monitor response to treatment over the course of hospitalization.

Two weeks after discharge home, another CANHELP questionnaire (ratings of satisfaction only) was mailed to patients in both cohorts at their homes. Patients in the second cohort also received a repeat ESAS tool. Participants were telephoned 2 weeks later if there was no response, and the questionnaire was sent a second time if there was no further response. If a caregiver survey was completed and the patient died, the follow-up survey was completed where possible. No interventions were provided based on post-discharge responses.

The Research Ethics Board at Queen's University Health Sciences and the Affiliated Teaching Hospitals Human Research Ethics Board approved the protocol as a quality improvement initiative. Participants received a verbal description of the process but were not required to give written consent.

Analysis

Given the pilot nature of the study, no sample-size calculations were performed and a convenience sample was used. Characteristics of CTU patients and caregivers were described as counts and percentages for categorical variables and as means with standard deviations for continuous variables.

For both cohorts, the main outcome was change in satisfaction with EoL care as measured by the CANHELP satisfaction questionnaire completed during hospitalization compared with after discharge. The satisfaction scores for the 10 improvement opportunities were compared before and after the intervention using paired *t* test.

Secondary outcomes were as follows: number of palliative care consults, referral to social work and home care services, death rates, and discharge destination. In the second cohort, in addition to the above-mentioned outcomes, we examined the change in ESAS scores (total and subsection scores) over the course of hospitalization.

Results

Of the 123 patients approached, 67 (54.5%) were recruited to the two phases of the project (33 for phase 1 and 34 for phase 2). Only 30 caregivers were available to be approached for the project and 13 of these (43.3%) agreed to participate. Figure 1 summarizes the reasons why patients and caregivers did not participate. The most common reason why patients did not wish to be involved was presence of symptoms or feeling overwhelmed by their illness. Demographic information for all study patients is shown in Table 1. The majority of patients (64.2%) had cancer as their primary diagnosis, while 23.9% had moderate to severe COPD. There were no patients with severe dementia as their inclusion diagnosis. The median PPS of patients was 50%.

The top 10 improvement opportunities are shown in Table 2. The most common issues in the top 10 were those related to self-care management, adequacy of home care services, and sense of being a burden on others. There was a statistically significant improvement in the overall mean satisfaction score of items that were ranked in the top 10 improvement opportunities. In the first cohort, the mean score at the initial visit was 3.2+/-0.7 and at follow-up was 3.8+/-1.0 ($p < 0.0001$). In the second group, the mean score at the initial visit was 3.1+/-0.8 and at follow-up was 3.4+/-1.1 ($p = 0.008$). The difference in the change in satisfaction scores between the two interventions was not significant at 0.3 ($p = 0.14$). Caregiver improvement opportunities are shown in Table 3. There was a statistically significant improvement of scores on the improvement opportunities (initial visit 2.8+/-0.9 vs. follow-up visit 3.3+/-1.2; $p < 0.0001$).

Figure 1 ***Patient and Caregiver Flow Diagram (Phases 1 and 2)***

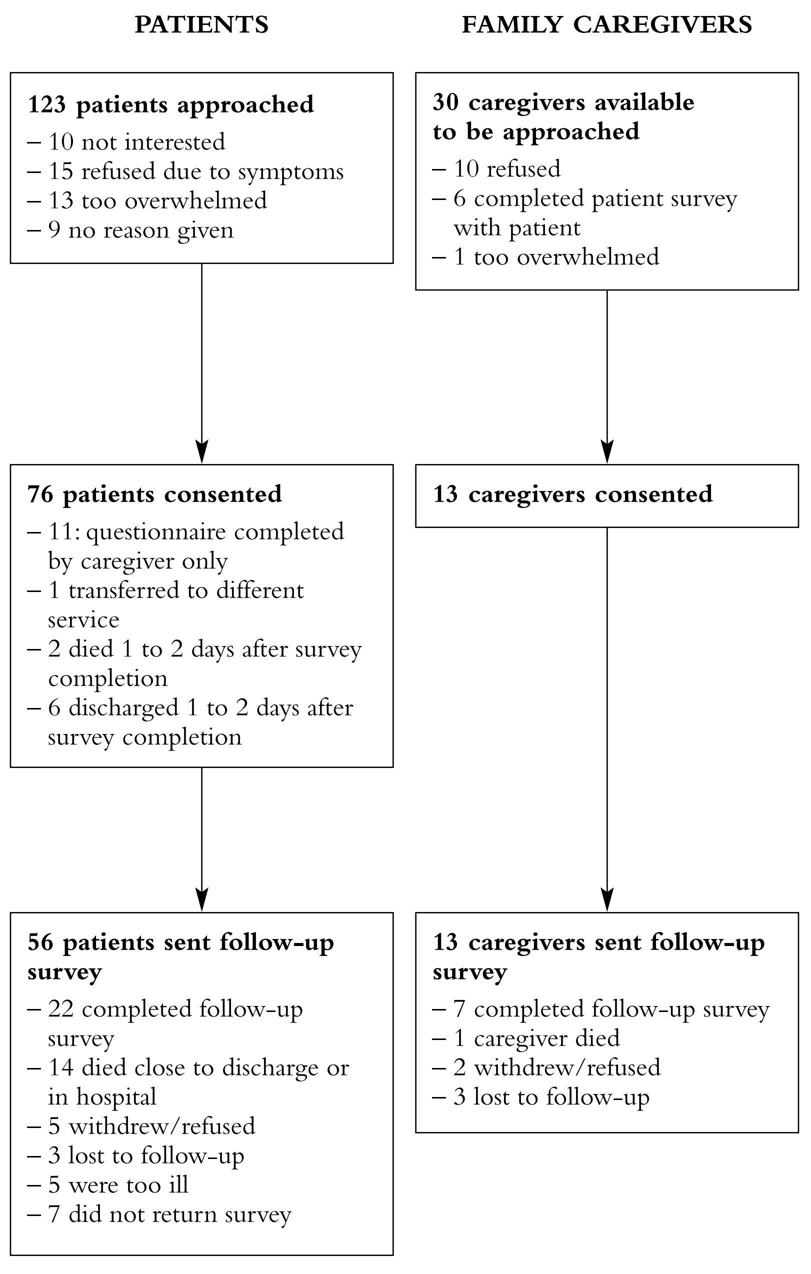

Table 1 ***Patient Characteristics***

	First Cohort $n = 33$ **(%)**	**Second Cohort** $n = 34$ **(%)**	p **value**
Gender			
Male	10 (30.3)	12 (35.3)	0.66
Female	23 (69.7)	22 (64.7)	
Age (mean ± *sd*)	76.1 ± 9.6	74.7 ±10.7	0.58
Age 80	8 (24.2)	5 (14.7)	0.32
Charlson Comorbidity Index (mean ± *sd*)	5.7 ± 2.6	5.0 ± 2.6	0.24
COPD	8 (24.2)	8 (23.5)	0.95
Heart failure	3 (9.1)	1 (2.9)	0.29
Cirrhosis	1 (3.0)	0 (0.0)	0.31
Cancer	22 (66.7)	21 (61.8)	0.68
PPS (mean ± *sd*)			0.52
30	3 (9.1)	2 (5.9)	
40	2 (6.1)	6 (17.6)	
50	10 (30.3)	10 (29.4)	
60	12 (36.4)	6 (17.6)	
70	3 (9.1)	5 (14.7)	
80	2 (6.1)	3 (8.8)	
90	1 (3.0)	2 (5.9)	
Marital status			0.40
Never married	2 (6.1)	0 (0.0)	
Married/common-law	14 (42.4)	19 (55.9)	
Separated/divorced	3 (9.1)	2 (5.9)	
Widowed	14 (42.4)	13 (38.2)	
Education			0.21
Elementary school	2 (6.1)	0 (0.0)	
High school	19 (57.6)	15 (44.1)	
College	11 (33.3)	12 (35.3)	
University	1 (3.0)	5 (14.7)	
Postgraduate	0 (0.0)	1 (2.9)	
Other (specify)	0 (0.0)	1 (2.9)	

(cont'd next page)

Table 1 (cont'd)	**(n = 33)**	**(n = 34)**	
Race			0.31
African/Black North American	1 (3.0)	0 (0.0)	
Caucasian	32 (97.0)	34 (100.0)	
Current employment status			**0.03**
Employed	2 (6.1)	1 (2.9)	
Unemployed	16 (48.5)	7 (20.6)	
Retired	15 (45.5)	26 (76.5)	
Admitted from			
Home, alone	9 (27.3)	6 (17.6)	0.35
Home, with relative	24 (72.7)	27 (79.4)	0.52
Retirement home	0 (0.0)	1 (2.9)	0.32
Urban area	13 (39.4)	23 (67.6)	**0.02**
Rural area	10 (30.3)	12 (35.3)	0.66
Discharge destination	**(n = 31)**	**(n = 34)**	
Home, alone	3 (9.6)	5 (14.7)	0.48
Home, with relative	15 (48.3)	19 (55.9)	0.39
Home, with paid supports	1 (3.2)	3 (8.8)	0.32
Nursing home	5 (16.1)	3 (8.8)	0.43
Palliative care unit	2 (6.4)	1 (2.9)	
Hospital mortality	5 (16.1)	6 (17.6)	0.78

Table 2 ***Top 10 "Improvement Opportunities" Identified by Patients***

Question: Over the last 4 weeks . . .	**Frequency**
Satisfaction with the level of confidence in ability to manage illness?	14
Satisfaction with the home care services you received?	12
Satisfaction patient not a burden on family or others?	10
Satisfaction with being able to do special things patient wished to do?	9
Satisfaction with knowledge of the doctors in charge of your care?	8
Satisfaction with help received with personal care?	8
Satisfaction with the level of confidence in the ability of a family member or friend to help you manage patient's illness?	8
Satisfaction with discussions with doctors about where patient would be cared for if a situation worsens?	8
Satisfaction with discussions with doctors about the use of life sustaining technologies?	8
Satisfaction with role in decision-making regarding medical care?	8

Table 3 ***Top 10 "Improvement Opportunities" Identified by Family Caregivers***

Question: Over the last 4 weeks . . .	**Frequency**
Satisfaction with degree of understanding what to expect at the end stage of their relative's illness?	6
Satisfaction with the level of confidence in ability to help relative manage his/her illness?	5
Satisfaction with the environment or the surroundings in which the relative was cared for?	5
Satisfaction with discussions with the doctors about the use of life sustaining technologies?	5
Satisfaction with ability to talk comfortably with relative about his/her illness, dying, and death?	5
Satisfaction with ability to manage the financial costs associated with relative's illness?	4
Satisfaction with updates received about relative's condition, treatments, test results etc. in a timely manner?	4
Satisfaction with discussions with the doctors about where relative would be cared for if he or she were to get worse?	4
Satisfaction that the doctors were available when caregiver or patient needed them?	3
Satisfaction with the level of trust and confidence in the nurses who looked after relative?	3

Overall, 32.8% of participants were seen by palliative care, 55.2% were referred to social work during their hospital stay, and 41.8% had a home care consultation prior to discharge. Compared to patients in the second cohort, patients in the first cohort were more likely to be referred to social work (69.7% vs. 41.2%; $p = 0.02$) and there was a trend towards increased referral rates to palliative care (42.4% vs. 23.5%; $p = 0.10$) and to home care services (51.5% vs. 32.4%; $p = 0.11$).

Scores on the ESAS during phase 2 are shown in Table 4. There was improvement in all scores, although nausea and drowsiness did not reach statistical significance.

Nurse facilitator interventions were not formally tabulated but a sample of recommendations made to medical staff arising from patient perspectives on improvement opportunities is shown in Appendix 1.

Table 4 ***ESEA Scores (1–10)***

	Initial (n = 29)	**Discharge (n = 29)**	**p value**
Pain	2.5 ± 3.2	1.2 ± 1.6	**0.001**
Nausea	0.6 ± 1.4	0.1 ± 0.4	0.06
Depression	2.0 ± 2.8	1.6 ± 2.3	**0.02**
Anxiety	2.8 ± 3.5	1.4 ± 2.0	**0.02**
Drowsiness	2.3 ± 2.3	2.1 ± 2.4	0.75
Appetite	4.0 ± 3.3	2.0 ± 2.3	**< 0.0001**[a]
Feeling of well-being	5.6 ± 2.5	3.9 ± 2.2	**< 0.0001**[a]
Tiredness	4.9 ± 2.6	3.0 ± 1.9	**0.001**
Sob	3.6 ± 2.8	1.9 ± 1.8	**< 0.0001**

[a] Lower score implies improvement of symptom.

Discussion

The CANHELP questionnaire has been developed and used in studies to assess patient and family perspectives on EoL care issues but has never been used as a screening tool to identify care issues for individual patients at high short-term risk of death. To identify such care issues, we asked patients and family caregivers to rate both the importance of and satisfaction with various EoL aspects of care. In this pilot study, we assessed the feasibility and impact of having a nurse facilitator use the CANHELP tool, in conjunction with a screening symptom assessment tool, on process measures and satisfaction with care.

We encountered challenges in enlisting the participation of eligible patients and their families. The large proportion of potential participants who refused to take part (47/123) highlights the difficulty in doing research with a sick, vulnerable population. Enrolment might have been more successful if the approach had been better integrated into the "usual" care processes rather than part of a formal, time-limited project entailing an informal consent process. It should be noted that patients who declined to participate due to being overwhelmed or due to uncontrolled symptoms had a high likelihood of benefiting from the approach. Thus our study may underestimate potential benefits from the intervention in a real-life setting.

For those patients and families who did participate, we observed small but statistically significant improvements in ratings of satisfaction with high-priority aspects of EoL care. In addition, we observed an overall improvement in ESAS scores; however, overall satisfaction did not improve with the addition of systematic symptom assessment. These improvements in ESAS scores in the second cohort were not associated with an increase in rates of referral to palliative care. Formal screening of symptoms in palliative care populations (rather than in general medicine patients) has been shown to be beneficial in identifying symptom issues. However, improvement of patient satisfaction and other positive outcomes arising from the identification of symptoms has not consistently been shown to improve outcomes (Homsi et al., 2006).

A limitation to this study was the uncontrolled design. The feasibility of the intervention was unclear and a primary purpose of the study was to assess this. Studies will now be able to examine the efficacy of the intervention using a superior study design.

The improvement opportunities that were identified represent care issues in which there is a gap between importance and satisfaction. Many of these opportunities may not have been identified in the course of routine care and their identification in the CANHELP likely contributed to the high rate of palliative care and social work referrals in the study. Several of the most common opportunities related to communication and EoL decision-making have been identified in previous studies using the CANHELP (Heyland et al., 2010b). Subsequent discussions with the nurse or facilitated by the nurse appeared to have an effect on satisfaction in these domains.

Although statistically significant changes were observed in satisfaction scores, the magnitude of the effect was low. While it was not formally measured, this effect may reflect inconsistent follow-up by medical staff on recommendations made by the nurse, despite good documentation of care issues and provision of a list of management options. The nurse found that members of the medical team followed suggestions to varying degrees. Frequent change of residents on the medical team (monthly) resulted in difficulties maintaining team awareness of the nurse's role and consistency in following the nursing recommendations. The challenge of advocating for EoL care issues found in this project reflects reports in the literature on nurses' perceptions and experiences of barriers to optimal EoL care on inpatient units (Thompson et al., 2006). These factors could possibly be reduced if the professional administering the intervention was a fully integrated and consistent member of the medical team. Studies with nurse navigators in oncology have shown the benefits of a similar role, but the nurses in these studies had the ability to implement many of the clinical interventions without having to rely on medical staff (Wells et al., 2008). Given the time needed to perform the role played by the nurse in our project, assigning it to medical house staff would not be feasible in most settings.

Despite the positive signals arising from this study on the use of the CANHELP questionnaire, there are limitations to its use in clinical practice. The average time that the nurse took to administer the tool was 20 to 30 minutes, which proved to be a challenge for patients who were medically unwell. This negative factor is countered by the therapeutic benefit of discussing the identified issues with a skilled nurse. Nurses working in a focused role or working in a broad role to improve overall care could use the CANHELP on a general medicine unit to link with the medical team to target satisfaction with EoL care.

Other limitations include the small number of patient and caregiver participants, which limited evaluation of the intervention's impact.

Although previous research has found that patient satisfaction related to hospital EoL care remains relatively stable after discharge, it is uncertain whether the observed changes in satisfaction were attributable to the nurse-led improvement intervention or to changes in location of care (from hospital to home) in this study (Heyland et al., 2009). As noted, there was no control group and the improvement in CANHELP and ESAS scores could relate to positive outcomes of "usual" care regardless of nurse facilitator interventions. As most of the care gaps identified by the CANHELP were not specific symptoms, the use of a concurrent symptom-assessment approach could serve to improve management. However, the impact cannot really be judged from this study.

Future research arising from this project should focus on the use of the CANHELP in ways that enhance the feasibility and impact of the intervention. A shorter version of the instrument is being developed. Perhaps integrating the measurement and implementation strategy into the role of existing team members, as a part of routine care (rather than having it administered by an external research nurse), will improve compliance and effect.

Conclusions

Using the CANHELP to guide management, the nurse role was relevant in identifying improvement opportunities in EoL care among internal medicine patients, improving symptom ratings, and making small improvements in satisfaction with care. Feasibility was limited by the recruitment process and by limited uptake of the nurse facilitator's recommendations by medical staff. Further work is necessary in other settings to further establish the feasibility and clinical usefulness of the CANHELP as a quality-improvement tool.

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Appendix 1 *CTU Support Services Project*

Improvement Opportunities (Patient Perspective): Sample Recommendation Sheet

Issue	**Importance**	**Satisfaction**	**Considerations**
Your doctor takes a personal interest in you and your medical problems.	5	2	• Consider holding a family meeting at patient's request • Consider being in contact with family physician during admission (shows that physician is up to date about current medical and personal status)
The doctors explain things relating to your illness in a way you can *understand*.	5	2	• Consider patient's education level • Consider a translator, if applicable • Consider patient's learning needs
You have trust and confidence in the doctors responsible for your care.	5	3	• Encourage honest discussions with the patient and family about prognosis, code status, and EOL care • Enhance rapport with the patient • Identify barriers to increased trust and confidence
You have trust and confidence in the nurses responsible for your care	5	3	• Encourage honest discussions with the patient • Enhance continuity of care • Enhance rapport with the patient • Identify barriers to increased trust and confidence
You feel confident in *your own ability* to manage your illness at home.	5	3	• Consult Community Care Access Centre (CCAC) to arrange for home care on discharge • Consider services to manage medications at home • Consult Occupational Therapy • Patient teaching re: management of illness – Pharmacy to educate about medications – Available services when patient is discharged – Long term care accommodations • Consider home supports available (i.e., family or friends) • Consider Long Term Care (i.e., nursing home, retirement home)

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Appendix 1 (cont'd)

Issue	Importance	Satisfaction	Considerations
You discuss options with your doctor(s) about where you would be cared for (in hospital, at home, or elsewhere) if you were to get worse.	5	3	• Consult palliative care • Encourage patient and family/caregiver conversation about expectations at end of life • Assist patient to make a personal plan of care for end stages of life • Discuss end of life care locations with patient (i.e. home, hospital, hospice etc.)
You are not a burden on your family or others you care about.	5	3	• Consult CCAC for home care services • Consider local hospice services • Encourage independence • Arrange for respite care
You are able to manage the financial costs associated with your illness.	5	3	• Consult social work • Consult CCAC
There are services available to look after your health care needs at home.	5	3	• Consult CCAC (Home Care Program) • Consider patient's accessibility to health care services • Consider private services, if patient can afford cost (service list available through Social work and CCAC) • Consider Seniors Managing Independent Living Easily (SMILE) program for community support services (www.von.ca)
The doctors and nurses looking after you are compassionate and supportive.	5	3	• Consider palliative care volunteer program • Consider HELP (Hospital Elder Life) program • Consult social work • Consult palliative care • Consult spiritual care (if applicable to patient)

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Résumé

Les perceptions qu'a le personnel infirmier en soins intensifs de son rôle dans les conflits entre la famille et l'équipe de soins relativement aux plans de traitement

Marie Patricia Edwards, Karen Throndson, Felicia Dyck

Les conflits concernant les plans de traitement sont une source de préoccupation pour les personnes qui travaillent dans le domaine des soins intensifs. Cette étude a pour but d'explorer et de décrire les perceptions qu'ont les infirmières et les infirmiers en soins intensifs de leur rôle dans les situations de conflit entre les membres de la famille et les fournisseurs de soins dans les services de soins intensifs. Suivant un plan d'analyse descriptive et qualitative, l'étude a comporté des entretiens individuels avec douze membres du personnel infirmier en soins intensifs et des entretiens de groupe avec quatre membres d'expérience. Ces personnes ont décrit leur rôle comme suit : fournir des soins sûrs, satisfaisants et de qualité aux malades; bâtir ou rétablir des relations de confiance avec les familles; et soutenir les autres membres du personnel infirmier. Elles ont attiré l'attention sur le niveau de stress dans les situations de conflit, le besoin de faire preuve de prudence dans la prestation des soins et dans les communications avec les membres de la famille, et le besoin de soutien du personnel infirmier. Les auteures concluent qu'il faudra faire d'autres recherches sur le travail dans les situations de conflit ainsi qu'améliorer la formation dans ce domaine pour le personnel infirmier en soins intensifs.

Mots clés : conflit, personnel infirmier en soins intensifs, famille, communications, confiance

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Critical Care Nurses' Perceptions of Their Roles in Family-Team Conflicts Related to Treatment Plans

Marie Patricia Edwards, Karen Throndson, Felicia Dyck

Conflict over treatment plans is a cause of concern for those working in critical care environments. The purpose of this study was to explore and describe critical care nurses' perceptions of their roles in situations of conflict between family members and health-care providers in intensive care units. Using a qualitative descriptive design, 12 critical care nurses were interviewed individually and 4 experienced critical care nurses participated in focus group interviews. The roles described by the nurses were as follows: providing safe, competent, quality care to patients; building or restoring relationships of trust with families; and supporting other nurses. The nurses highlighted the level of stress when conflict arises, the need to be cautious in providing care and communicating with family members, and the need for support for nurses. More research related to working in situations of conflict is required, as is enhanced education for critical care nurses.

Keywords: conflict, critical care nurses, family, communication, trust

Introduction

A hallmark of critical care nursing is the proximity of nurses to patients and their family members (Malone, 2003). This provides nurses with the opportunity to come to know a patient's pattern of responses to treatment and the patient as a person and as a family member (Benner, Hooper-Kyriakidis, & Stannard, 1999; Benner, Tanner, & Chesla, 1996; Edwards & Donner, 2007; Malone, 2003; Tanner, Benner, Chesla, & Gordon, 1993). This proximity also means that when conflict arises over treatment plans, nurses are likely to be the members of the health-care team with the most contact with the patients and family members involved (Halcomb, Daly, Jackson, & Davidson, 2004; Peter & Liaschenko, 2004). Although conflict is known to be an issue of concern in the intensive care unit (ICU), we have limited knowledge about the role of critical care nurses in situations of conflict.

Conflict in the ICU

Conflict is not uncommon for those working in critical care settings. In a survey of 7,358 ICU staff members in 24 countries, 72% of respondents had experienced at least one situation of conflict in the week the questionnaire was completed, with 27% of conflict occurring between patients' families and health-care providers (Azoulay et al., 2009). The most common sources of conflict were behaviour issues (e.g., mistrust, communication gaps) and concerns related to end-of-life care (e.g., patient preferences were ignored). In other studies, conflict was identified in 32.1% of 656 adult patients with prolonged stays in ICU (Studdert et al., 2003) and in 78% (*n* = 102) of adult patients when discussions had taken place regarding withholding or withdrawing life-sustaining treatment (Breen, Abernathy, Abbott, & Tulsky, 2001). In those studies, disagreement between family and staff accounted for approximately half of all conflict. Families of adult ICU patients have also reported family-staff conflict related to treatment decisions, communication, and unprofessional behaviour (Abbott, Sago, Breen, Abernethy, & Tulsky, 2001; Norton, Tilden, Tolle, Nelson, & Eggman, 2003).

It is not only the frequency of conflict over treatment plans that is worrying, but also the fact that conflict can be difficult to address. A group of clinical bioethicists in Toronto, using a modified Delphi survey technique, identified the top ethical challenge in health care as disagreement between patients/family members and health-care providers regarding treatment decisions (Breslin, MacRae, Bell, Singer, & University of Toronto Joint Centre for Bioethics Clinical Ethics Group, 2005). This disagreement was described as involving either patients or family members requesting treatment options that were deemed inappropriate by the team, or team members proposing treatment options that patients or family members would not accept, with the most charged and intractable examples occurring at end of life in critical care settings. In the past few years, at least three cases of conflict over treatment decisions in ICU have been heard in Canadian courts (*Golubchuk v. Salvation Army Grace General Hospital et al.*, 2008; *Jin (next friend of) v. Calgary Health Region*, 2007; *Rasouli v. Sunnybrook Health Sciences Centre*, 2011). Work has been done to develop strategies to prevent or mitigate conflict in ICUs, including the use of structured family meetings within 72 hours of admission (Lilly et al., 2000), a screening tool to identify families at risk for conflict followed by interventions aimed at improving family-team communication (Burns et al., 2003), and interactive workshops to improve communication within teams and with families (Hales & Hawryluck, 2008).

Nurses and Conflict in the ICU

While nurses have participated in studies exploring the prevalence and characteristics of conflict in ICU settings (Azoulay et al., 2009; Breen et al., 2001; Danjoux Meth, Lawless, & Hawryluck, 2009; Studdert et al., 2003), we found only two studies that explicitly explored the roles or responses of critical care nurses in situations where disagreement over treatment plans was present. Jezewski (1994) used interviews to explore, with 22 critical care nurses, the experience of interacting with patients or family members as a decision was made regarding resuscitation status. Conflict was identified as a core category in this grounded theory study, with two subcategories evident: interpersonal and intrapersonal. Interpersonal conflict could occur among family members, between family members and health-care providers, or between health-care providers. The nurses described roles in both preventing and resolving conflict through "brokering care," which included "advocating, negotiating, mediating, and most importantly being sensitive to the needs of patients and families" (p. 464). There was more discussion of the roles in preventing conflict than those in dealing with conflict when it arises.

Robichaux and Clark (2006) examined the actions of critical care nurses in situations where aggressive treatment continued when the nurse believed the patient would not regain "an acceptable quality of life despite the provision of all therapies and interventions" (p. 481). Nurses (N = 21) described their responses to these situations in terms of (a) protecting or speaking for the patient, particularly in relation to preserving patient autonomy; (b) presenting a realistic picture to family members with regard to recovery; and (c) experiencing resignation and frustration due to feelings of moral responsibility and an inability to change how events would unfold. The nurses' stories involved a particular type of disagreement: situations where patient treatment wishes conflicted with family or physician desire for more aggressive interventions. Other types of disagreement were not considered. In addition, the researchers examined only the perspectives of nurses recognized as "experts" by colleagues.

Clearly, there is a gap in our understanding of critical care nurses' experiences with conflict. The purpose of this study was to explore and describe critical care nurses' perceptions of their roles in situations of conflict between family members and health-care providers in the ICU. The definition of conflict used in this study was "a dispute, disagreement, or difference of opinion related to the management of a patient in the ICU involving more than one individual and requiring some decision or action" (Studdert et al., 2003, p. 1490). The research question was as follows: *What roles do critical care nurses assume in situations where patients are unable to express their wishes due to illness/injury, family members act as surrogate decision-makers, and family members and health-care providers disagree about treatment decisions?*

Methods

A qualitative descriptive design was used to explore the research question. In this type of study, researchers "offer a comprehensive summary of an event in the everyday terms of those events" (Sandelowski, 2000, p. 336). Approval was obtained from the University of Manitoba research ethics board. Two recruitment strategies were used: an invitation to participate in the study was e-mailed to all Manitoba members of the Canadian Association of Critical Care Nurses, with the assistance of the Association; and a recruitment notice was placed in the newsletter of the Manitoba chapter of the Association. To participate, individuals were required to have worked as a registered nurse in an ICU for a minimum of 1 year. As only three nurses volunteered to participate, permission was obtained from the research ethics board to have the College of Registered Nurses of Manitoba send invitations by regular mail to all nurses who self-reported as working in an ICU in one of two tertiary care teaching hospitals. Interested individuals contacted the principal investigator (MPE) by phone or e-mail and a meeting was arranged. All nurses gave written informed consent prior to being interviewed.

Data were collected through interviews using a semi-structured guide developed by the researchers. Open-ended questions explored participants' experiences with situations of conflict, sense of the role of the nurse in these situations, and thoughts on addressing conflict. The nurses were asked to tell a story from their practice about a situation involving a dispute or disagreement between family members and health-care providers over the plan of care; then questions were asked about the nurse's role in those situations. Field notes were kept, and these informed the revision or addition of questions on the interview guide. Two nurses were interviewed twice in order to clarify comments from the first interview and ten were interviewed once. Interviews ranged in length from 45 to 90 minutes, were held in a private office or at the nurse's home, were carried out in English by the principal investigator, and were audiorecorded and transcribed. To ensure privacy, members of the research team signed a confidentiality pledge, data were stored securely, and identifying information was removed from transcripts.

Following the individual interviews, letters were sent to eight experienced critical care nurses, known to the principal investigator because of their leadership roles, inviting them to take part in a focus group to discuss insights and patterns evident in the individual interviews. It was felt that a focus group of four to six persons would yield a rich discussion (McLafferty, 2004). It proved challenging to schedule one focus group meeting, so two separate meetings were held, in private offices, with two experienced nurses present at each; these individuals also gave written informed consent. Each group interview was carried out by the principal investigator, lasted approximately 90 minutes, and was audiorecorded and transcribed.

Data analysis and collection took place concurrently and the process fit the description of conventional content analysis provided by Hsieh and Shannon (2005). All team members were involved in this process. Team members read each transcript carefully to get a sense of the whole, and descriptive words or phrases (Benner et al., 1996) were written in the margins of the transcript to capture meaning. Meetings of research team members were held to discuss the nurses' responses to interview questions, compare phrases written in the margins of transcripts, reach agreement on categories, refine categories, and identify themes based on patterns.

Morse, Barrett, Mayan, Olson, and Spiers (2002) define "verification" as "the mechanisms used during the process of research to incrementally contribute to ensuring reliability and validity, and, thus, the rigor of a study" (p. 17). To ensure the descriptive validity or "factual accuracy" (Maxwell, 1992, p. 285) of the account presented, interviews were audiorecorded and transcribed, transcriptions were checked for accuracy, and data were managed using Ethnograph software. Data collection and analysis moved forward concurrently and interview questions evolved based on early patterns evident in nurses' responses (Morse et al., 2002). To promote interpretive validity in the analysis process, attention was paid to the "the language of the people studied" (Maxwell, 1992, p. 289). In addition, there was constant movement back and forth within transcripts and between transcripts as the team met to identify categories, patterns, and themes. The focus group interviews with experienced critical care nurses to discuss patterns and themes in the data were used as a strategy to ensure the credibility of the findings (Sandelowski, 1986).

Sample

A convenience sample of 12 critical care nurses volunteered to take part in the individual interviews. They worked in medical, surgical, or mixed ICUs. Eleven nurses worked in tertiary care, university-affiliated teaching hospitals and one worked in an ICU in a community hospital where medical residents were not present; six worked full-time and six part-time. Their mean age was 40.6 years (n = 11) and the mean experience was 17.2 years in nursing and 12.3 years in ICU (n = 12). Seven of the nurses were degree-prepared and five diploma-prepared and all but one had completed an ICU course.

Following the individual interviews, four experienced critical care nurses met with the principal investigator for a focus group interview. Their mean experience was 24.5 years in nursing and 21.75 years in critical care, with the majority of that experience in tertiary care, university-affiliated teaching hospitals. All had completed a university degree program and an ICU course.

Findings

In the individual interviews, each nurse told a story about a situation of conflict from practice. All but one of those situations was characterized by the nurse as end-of-life or involving decisions about withdrawal of treatment, with the majority involving family desiring more aggressive treatment than was recommended by the team. Most situations were characterized by differences between the family and the team, with the nurses and physicians having a strong sense of an expected downward trajectory of the illness and the family holding out hope for recovery. In three of the end-of-life situations, culture was mentioned as a factor in family decision-making. Conflict was expressed in a number of ways but could involve family behaviours perceived as demonstrating surprise at the proposed plan, suspicion of team members, confusion, and/or anger.

From these stories and from the nurses' responses to interview questions, four themes were identified. The first, *heightened stress in an already stressful place,* is a broad contextual theme, placing conflict situations in the context of the ICU. The other three relate to nurses' roles in situations of conflict. The themes are: *the patient comes first; building relationships, building trust;* and *supporting each other.*

Contextual Theme: Heightened Stress in an Already Stressful Place

The nurses described their work environments as stressful due to the acuity of patients' conditions, the unpredictable nature of patients' illnesses, the fear and anxiety exhibited by families, the complexity of the technology used, and the rapid pace of change. All of the nurses indicated that conflict could heighten stress in the already stressful environment of the ICU. One nurse stated, "Family conflict is one of the greatest stresses that I face when I go to work." Given nurses' proximity to the patient, the nurses identified how conflict could cause more stress for nurses than for other team members, as nurses worked with the patient and family "every hour, minute-to-minute, dealing with the conflict," whereas other team members "speak to the family, and they leave."

The responses to heightened stress in situations of conflict were varied. Some nurses indicated that it affected how they thought about their work and their patient assignment. One participant stated, "You didn't want to come to work, you did not want to be in that room, you didn't want to be the nurse there." Others noted that they or their colleagues, when assigned to the care of a patient where conflict was known to be present, responded by "backing away" from the family. This was described as a strategy to protect the nurse from the emotional costs of the conflict. One of the ways they did this was by controlling visitation, as described in this excerpt:

> *[Some nurses] do back away. They try and avoid confrontations. They're not comfortable with that. They . . . minimize their contact with the family. They'll sometimes — I don't know if they mean to, but they may have the family come in and then go for break and redirect all of their questions to the [charge nurse] or even to the physicians that are on.*

While "backing away" was evident in some of the situations described by nurses, and was associated with a prolonged stay and nurse-family interactions over time, the more common response in the stories told was to engage the family while proceeding with caution in terms of how they communicated with the family and what they said and did. One person described this as being "on guard" so as not to "escalate the conflict."

The other themes relate to the roles of the critical care nurse in situations of conflict. Even in the presence of heightened stress and an environment that caused nurses to be cautious in their interactions with patients and families, it was evident in nurses' stories and comments that a great deal of work went into caring for the patient and building or restoring relationships of trust with family members in the ICU. The three themes below illustrate the roles that nurses assumed as they cared for patients, worked with families, and supported each other in situations of conflict.

The Patient Comes First

All of the nurses highlighted the role of the nurse in conflict situations of focusing first on providing safe, competent, quality care to the patient and in bringing forward knowledge about patients to other team members. Some nurses described their perspective as seeing the "big picture" or the "whole picture":

> *It seems like my role as a nurse a lot of the time is to think of the big picture, because so often it feels like the attending physicians are so focused on certain medical problems — like the lungs or a certain body system — they are not seeing what I think is the whole picture.*

Nurses would describe for the attending physician, many of whom spent 1 week at a time in the unit, "the whole span of events," as "they aren't seeing . . . the months of care that have gone into taking care of a patient." This "whole picture" perspective could also involve coming to know the patient and his/her wishes regarding treatment through advance directives or through the family, if the patient no longer could express his/her wishes, and bringing those wishes forward to other team members. Knowledge or information about the patient and the illness trajectory could put the conflict over the treatment plan into a temporal context, shed light on its sources, or point to the need for a family meeting.

Building Relationships, Building Trust

All of the nurses stated that an essential aspect of their work in the ICU was establishing and building relationships of trust. This was particularly true in situations of conflict. Nurses saw themselves as well situated for this relationship-building role:

> *We have the gift, really, of time with the families and establishing a rapport . . . so we really are, I think, very key in laying the foundation for what's going to come. . . . Trust takes time, and we have the ability to give the patient and the family that.*

It was acknowledged that there was much about the dynamic and uncertain ICU environment that made it challenging to nurture relationships of trust. One nurse noted that "the stakes are high" because they were frequently talking about "life and death" situations and the credibility of the nurse or the team "can slip away pretty quick." Not only could patients' conditions change rapidly, but shift workers came and went, new resident physicians circulated through units, and different attending physicians assumed responsibility for patient care each week. The challenges associated with the changing of attending physicians were discussed by all of the nurses and included the possibility of altered patient care plans, which could cause or increase conflict.

To build or restore relationships of trust in the presence of conflict, nurses emphasized the value of having consistent caregivers for patients, demonstrating competence and caring in working with the patient and family, communicating effectively with the family and with other team members, and collaborating with others (e.g., physicians, spiritual care providers, social workers) to support the family. The nurses stressed the importance of communication in building trust with families, while acknowledging the need for caution. This caution related to ensuring that the information provided was accurate, honest, and consistent with what had been communicated by others to promote trust in both the nurse and the team:

> *If there has been conflict, you become even more vigilant in making sure you don't . . . increase the conflict, potentially, or decrease the credibility of the team, thereby making the family feel less secure.*

It was deemed essential to listen to family members and assess their understanding of the patient's condition. Nurses also played a role in reinforcing information provided by others.

Nurses described "planting the seeds" or "setting the stage" for families before conversations or meetings with physicians and acting as a "translator" or "interpreter" after these meetings:

> *A lot of times I feel like I need to help prepare the families for an in-depth discussion, or maybe a difficult discussion that I know is coming up, just to kind of plant the seeds in some families' minds. A lot of the doctors will come in and they'll have . . . what seems like a very brief discussion about a certain medical decision or medical issue. And I can see that the family is — maybe the doctor has explained it in terms that are too detailed, or maybe the family is processing too much at one time. And so I'll try to revisit that later on, explain it in maybe more lay terms for the family.*

Nurses saw themselves as a bridge or link between families and physicians, highlighting their role in passing along knowledge about the family at rounds. In the presence of conflict, it became particularly important to seek clarity in the goals of care, alert physicians to family concerns, and advocate for family meetings. Another aspect of communication was interacting with other team members, including social workers, spiritual care providers, and psychiatric liaison nurses, to refer families for support and to exchange knowledge about the conflict situation.

Supporting Each Other

All of the nurses spoke of the importance of being supported in situations of conflict. The ends of the continuum in terms of support are exemplified by two comments:

> *You had the physicians, who were basically wanting to stay away, and they were distancing. And the nurses were left to deal with this whole scenario. There wasn't much support given to the bedside nurses by management, either. . . . It was so that people were saying, "Maybe I should phone in sick" [or] "No, I don't want to be involved with that family."*

> *The reason why I think it was handled well was because as a nurse I felt supported. I felt supported by my colleagues, I felt supported by my unit manager, I felt supported by the physicians. And then you can manage anything, right? When you feel that you are in a team, and you are working at this together, and your goal is to take care of the patient, you all have the same goal.*

When nurses did not feel supported, as in the first of the above two excerpts, it could have an effect on staff morale. Nurses stated that while it was important for managers to be supportive and that formal debriefing sessions could prove helpful in the midst of or after a situation of conflict, it was their nursing colleagues who were the most supportive of them on a moment-to-moment basis. This support could involve listening to the nurse's concerns, offering ideas or suggestions for working with families, offering assistance with patient care, or relieving the nurse for breaks. This ongoing support was viewed as an important nursing role in situations of conflict.

Discussion

The purpose of this study was to explore and describe critical care nurses' perceptions of their roles in treatment plan conflict between family members and health-care providers in the ICU. The nurses in this study did not see their roles in the presence of family-team disagreement as being much different from the roles they assumed in other patient-care situations. What was different in situations of conflict was threefold: the perceived level of stress when conflict arose; the need to be "on guard" when providing care and communicating with family members, so as not to escalate the conflict; and an increased need for support of nurses.

When thinking about treatment plan conflict, it is important to acknowledge that nurses work the "in-betweens" in practice settings (Varcoe et al., 2004, p. 323). This is a place of opportunity and challenge for nurses (Bishop & Scudder, 1996), a place from which bridges can be built to enhance families' trust in nurses and the team, and a place of "conflict and tension" (Varcoe et al., 2004, p. 323). The nurses in this study described both building bridges and experiencing tension with conflict. It has been recognized that nurses play a significant role in the development of trusting relationships with patients and families (Liaschenko, O'Conner-Von, & Peden-McAlpine, 2009; Peter & Morgan, 2001; Rushton, Reina, & Reina, 2007; Sellman, 2006, 2007). In writing about relational ethics, Bergum (2012) indicates that relationships are "the space where health care professionals and patients make connection" (p. 127). The same can be said of relationships with families. Two themes identified by Bergum as "giving language" (p. 129) to relational ethics are mutual respect and engagement. Much of the work described by the nurses in the present study was focused on engagement, on gaining trust by being competent and caring, listening and communicating effectively, responding to and passing along family concerns, and mobilizing resources. But the nurses were cautious in their engagement and were concerned about escalating the conflict, and it is not clear how this affected their relationships.

The nurses acknowledged that some people "back away" or disengage from families in the presence of treatment plan conflict. This finding is similar to that of Badger (2005) in a study on coping strategies, where medical ICU nurses (*N* = 24) used "retreating, avoiding, and distancing behaviors" (p. 67) to cope in "complex patient care situations" (p. 66). Robichaux and Clark (2006) also describe the potential for "disengagement" from families with prolonged "suffering" (p. 487) related to conflict. Such behaviours are cause for concern, as it has been found that withdrawing from families can increase their distress (Wiegand, 2006). The notion of backing away from families draws attention to both the emotional costs of conflict for nurses and the distress nurses may experience when not connecting with families. Workman, McKeever, Harvey, and Singer (2003) report that physicians (*n* = 6) and nurses (*n* = 6) in the ICU found it "very upsetting" when there was a "severe breakdown" in relationships (p. 20). More research is needed to explore this notion of backing away from families when conflict arises, to understand its dimensions and the knowledge, skills, and support needed by nurses to engage families in challenging circumstances.

While it is not surprising that conflict situations were viewed as heightening stress in the already stressful ICU environment, the extent to which the nurses talked about it must be acknowledged. Being cautious in one's actions and communications requires energy and attentiveness. In addition, nurses may experience moral discord in the face of disagreement over the plan of care (Badger & O'Connor, 2006). The nurses in our study expressed concern about the possible harm to patients of continued aggressive treatment, while acknowledging the angst of families in the face of the critical illness. The nurses were particularly concerned that they might contribute to patients' suffering. Clearly, disagreement over the plan of care can have an impact on nurses' perceptions of their work environments and their relationships. Poncet et al. (2007) found that the quality of working relationships, including the presence of conflict, was associated with severe burnout syndrome in critical care nurses (*n* = 1,937) in France. All of this underscores the importance of education regarding conflict and the importance of support from colleagues and managers in situations of conflict (Cronqvist, Lutzen, & Nystrom, 2006; Robichaux & Clark, 2006; Wall & Austin, 2008).

There are limitations to this study. A convenience sample of 12 nurses was used and the participants were experienced in nursing and in critical care. Less experienced nurses could have different perceptions of their roles in conflict. This question needs to be explored, and is especially important given the trend to hire new graduates into critical care settings (Halcomb, Salamonson, Raymond, & Knox, 2011). Only one of the participants worked in a community hospital, and that nurse's experiences were similar to those of the other nurses. It is acknowledged, however, that the realities of a non-teaching, community hospital may be different from those of a tertiary care teaching hospital, given that access to physicians, supports for families (e.g., psychiatric liaison nurses), and supports for nurses may be more limited and families may be interacting with fewer players, given the absence of residents. Finally, interviews were used to collect data, and the addition of observations, though difficult to arrange, could add rich data and deepen our understanding of nurses' roles in conflict.

As Fassier and Azoulay (2010) state, "because conflicts are inherent in all human activities, ICU conflicts are unavoidable" (p. 663). While it is essential that work on preventing conflict continue, it is also critical that we gain a greater understanding of the roles that critical care nurses play in working with families in the midst of conflict. The findings of this study add to our understanding of those roles, and extending this knowledge will help nurses to provide quality care to patients and families in the ICU.

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Résumé

Un examen des interventions actuelles en matière d'enseignement au patient menées auprès de patients de diverses cultures ayant subi un pontage aortocoronarien

Suzanne Fredericks, Souraya Sidani,
Mandana Vahabi, Vaska Micevski

Les initiatives actuelles en matière d'enseignement au patient devant subir une chirurgie cardiaque reposent sur la rétroaction de personnes originaires de l'Europe occidentale. On ne connaît pas leur pertinence dans le cas de patients d'autres origines. Les auteures de cette étude ont examiné la pertinence culturelle d'initiatives d'enseignement qui ont été menées auprès de patients de diverses origines ayant subi une chirurgie cardiaque. L'étude, qui comptait 242 participants, a été réalisée selon un modèle d'analyse descriptive non expérimentale. La pertinence culturelle a été évaluée en se fondant sur les comportements d'autogestion de la santé adoptés comme il était recommandé dans l'initiative d'enseignement au patient. Il a été constaté que pendant la première semaine suivant leur congé de l'hôpital, les participants d'une autre origine que l'Europe occidentale prenaient part à davantage d'activités liées au travail et affichaient moins de comportements d'autogestion de la santé que leurs homologues originaires de l'Europe occidentale, indiquant ainsi un manque de respect des recommandations. Cette étude fournit certaines données préliminaires suggérant que les initiatives actuelles d'enseignement au patient en matière d'autogestion de la santé ne sont pas pertinentes d'un point de vue culturel. Il sera nécessaire d'effectuer d'autres évaluations pour déterminer les raisons pour lesquelles des groupes culturels donnés adoptent certains types de comportements.

Mot clé : enseignement au patient

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An Examination of Current Patient Education Interventions Delivered to Culturally Diverse Patients Following CABG Surgery

Suzanne Fredericks, Souraya Sidani,
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The design of current educational initiatives for heart surgery patients is based on feedback from individuals of Western European origin. The relevance of these initiatives is unknown when provided to individuals from non-Western European cultures. This study examined the cultural relevance of heart surgery patient educational initiatives delivered to individuals of diverse backgrounds. It used a non-experimental descriptive design involving 252 participants. Cultural relevance was assessed through self-care behaviours performed as recommended in the educational initiative. The participants of non-Western European origin were found to engage in more work-related activities and fewer self-care behaviours than their Western European counterparts in the first week following hospital discharge, indicating lack of adherence to educational recommendations. The study provides preliminary evidence suggesting that current self-care educational initiatives may not be culturally relevant. Continued evaluation to determine reasons why specific cultural groups engage in specific types of behaviour is needed.

Keywords: adult health, cardiovascular disease, clinical nursing research, patient education

Introduction

Coronary artery bypass graft (CABG) is a common surgical treatment for cardiovascular disease. In the Canadian province of Ontario, every year an average of one in every one thousand individuals undergo a CABG procedure (Cardiovascular Health and Services in Ontario, 2005). Despite its benefits, CABG results in changes in the individual's physical and psychological functioning within the first 3 weeks following surgery (Cebeci & Celik, 2007). These changes increase the need for specific self-care behaviours post-discharge (Cebeci & Celik, 2007; Heart and Stroke Foundation of Canada, 2008). In the current inpatient cardiovascular surgical (CVS) setting, post-operative CABG patient education is usually provided (Johansson et al., 2004). Since the intended outcome of this education is increased performance of self-care behaviours (Johansson et al., 2004), CABG post-operative education programs address self-care behaviours. The majority of these programs have been designed, evaluated, and shown to be relevant using homogeneous samples of Canadians of Western European (WE) origin (Fredericks, Lo, Ibrahim, & Leung, 2010; Fredericks, Sidani, & Shugurensky, 2008). While CABG post-operative education programs are used throughout southern Ontario, their relevance for Canadians of non-WE origin has not been demonstrated.

According to Statistics Canada (2006), approximately 72% of the current Canadian population diagnosed with cardiovascular disease (CVD) (statistics reflect proportion of population with "heart disease") are of non-WE origin. In particular, individuals from India (37.3%) and China (14.0%) make up the two cultural groups most frequently diagnosed with CVD. Of these, 32.5% of the individuals who gave their country of origin as India and 24.1% of the individuals who gave their country of origin as China underwent CABG surgery in 2005–06.

Purpose

The purpose of this study was to examine the cultural relevance of current post-operative CABG patient education programs. Specifically, the aim was twofold: (1) to assess and compare the type of self-care behaviours engaged in by Canadians who give their country of origin as WE and those who give their country of origin as non-WE (in particular, individuals from India and China); and (2) to examine the difference in the number of self-care behaviours engaged in by Canadians who give their country of origin as WE and those who give their country of origin as non-WE (in particular, individuals from India and China).

Theoretical Underpinnings and Literature Review

Culture and Cultural Relevance

Ethnicity is an individual's ancestry, language, customs, religion, culture, and nationality. One aspect of ethnicity is culture, which refers to behaviours that are shared and transmitted within a society (Wildes & Emery, 2001). In particular, culture encompasses the values, beliefs, attitudes, and customs that are shared by a group of people and passed from one generation to the next. Culture has a considerable impact on how patients access and respond to health-care information. For example, individuals draw on their personal experiences and traditions to learn from their own culture how to be healthy, how to recognize illness, and how to be ill. The meanings attached to the notions of health and illness are related to the culture-bound values that shape how experiences are defined and perceived. A specific component of culture is cultural classification, which relates to the group (White [English, Irish, Scottish)], Indian, Chinese) or country (England, Ireland, Scotland, India, China) with which an individual identifies.

Cultural relevance refers to the extent to which interventions are consistent with the values, beliefs, and desired outcomes of a particular community (Yamazaki, 2005). One measurable indicator of relevance is effectiveness. In the health-care setting, failure to ensure cultural relevance can result in cultural biases and can significantly affect the way an intervention is perceived and hence implemented. For interventions to be culturally relevant, investigators must have knowledge of the community's cultural values and beliefs in order to develop and implement programs that are perceived as culturally acceptable (Yamazaki, 2005). The use of culturally acceptable treatments and interventions results in increased adherence, which results in turn in improved outcomes.

Relevance of CABG Patient Education Materials in Producing Changes in Self-Care Behaviour

Four studies, using randomized controlled trials and quasi-experimental designs, investigated the effectiveness and relevance of CABG patient education interventions in producing changes in self-care behaviours (Fredericks, 2009; Fredericks et al., 2008; Harkness et al., 2005; Moore & Dolansky, 2001). Relevance was measured using self-report measures. More than 90% of the sample in each of the studies contained individuals who identified their cultural background as WE. Cultural generation was not given in any of the studies. Results indicated a significant increase ($p < 0.05$) in the performance of self-care CABG behaviours following hospital discharge. The relevance of CABG patient education materials across culturally diverse groups (i.e., Indian and Chinese) has not been determined.

Relevance of Patient Education Materials Across Various Populations

Although the cultural relevance of CABG patient education in non-WE samples has not been examined, the cultural relevance of patient education materials in culturally diverse samples, including adults diagnosed with heart disease (Moreno et al., 1997), children with chronic illness (Povlsen, Karlberg, & Ringsberg, 2008), and adults with diabetes (Brown, Garcia, Kouzeranani, & Hanis, 2002; Hawthorne, Mello, & Tomlinson, 1993), has been explored. Randomized control designs, focus groups, and case studies were used to examine the relevance of patient education content in a diverse group of participants that included individuals who gave their country of origin as Pakistan (Hawthorne et al., 1993), Morocco, Turkey, Somalia, Eritrea, Iraq, Iran, Palestine, Afghanistan (Povlsen et al., 2008), El Salvador (Moreno et al., 1997), or Mexico

(Brown et al., 2002). In three of the four studies, cultural relevance was assessed by examining the difference between specific cultural groups and subgroups in terms of the number and type of behaviours performed. In one study, cultural relevance was examined using open-ended questions. The findings indicate that educational interventions that are culturally relevant promote increased understanding, implementation, and maintenance of recommended self-care behaviours identified in educational materials.

While there has been much interest and work in evaluating the cultural relevance of CABG patient educational interventions using a WE homogeneous sample, there does not appear to be any work addressing the relevance of CABG patient education materials for individuals with non-WE backgrounds. There is some support for the impact of culture in shaping individuals' perception of educational materials and their response to these resources (Brown et al., 2002; Hawthorne et al., 1993; Moreno et al., 1997; Povlsen et al., 2008; Yamazaki, 2005). A focused, in-depth understanding of this issue is necessary to inform the development of culturally competent, context-specific educational materials for enhancing self-care behaviours in patients who have undergone CABG surgery.

Methods

Research Design

A quantitative, non-experimental design was used. Approval for the study was received from the research ethics boards at the participating institutions.

Setting

The settings for the study were CVS units at two university-affiliated teaching hospitals in a large Canadian city. The accessible population included approximately three thousand CABG patients each year. These individuals underwent CABG surgery entailing one to four grafts. The average length of stay on the unit was 5 days (step-down CVS units). The average age was 68 years. The male/female ratio was 3:1. The ethnic distribution (as self-identified) was as follows: WE (English, Irish, or Scottish), 38.9%; Indian, 32.5%; Chinese, 24.1%.

Sample

Individuals were eligible for the study if they had undergone CABG surgery for the first time, with no additional surgical interventions; spoke English; were oriented to time, place, and person; and had access to a working phone at home.

Non-proportional quota sampling was used to stratify based on cultural group and to accrue participants. Calculation of sample size was based on (1) the number of groups to be compared (three: WE, Indian, Chinese); (2) an alpha level of 0.05 (to avoid a type II error); (3) a preset beta level or power of 0.8; and (4) a moderate effect size of 0.6 on self-care behaviour performance based on theoretical (Redman, 2007) and empirical (Fredericks, 2009; Harkness et al., 2005) evidence. Therefore, n = 75 patients were required for each group and the desired sample size was 225 (three cultural groups of 75 patients each).

Loss due to follow-up was anticipated, as previous studies examining patient education interventions in a CABG population report attrition rates of 10% (Fredericks, 2009; Harkness et al., 2005). In anticipation of dropouts, 10% over the required number of patients were recruited. The adjusted sample size was 249 (rounded up to this figure so that the three groups would have an equal number of participants) — 83 in each cultural group. The final sample size was 252. As there was unequal distribution across cultural groups, the groups were collapsed into WE and non-WE (Indian and Chinese) clusters.

Procedure

All patients received usual post-operative self-care standardized patient education in written format provided 24 to 48 before admission to the CVS unit. The education was developed by expert CVS nurses. The content of the usual education addressed the following: salt intake; fluid restrictions; an overview of the function of common medications (such as beta-blockers, ACE-inhibitors, warfarin, and analgesics) along with an overview of strategies that patients can use to remember to take their medication; activity performance (such as lifting objects, climbing stairs, walking, and sexual activity); and follow-up appointments. Nurses reviewed the usual self-care education materials with patients during a single one-on-one interaction during their post-operative hospitalization. This interaction varied in length from 3 to 10 minutes. After the materials were reviewed with the nurse, the patient was encouraged to continue to review and adhere to self-care behaviours outlined in the educational materials post-discharge.

Data related to performance of self-care behaviours were collected at baseline (upon entry into the study — that is, 24–48 hours pre-discharge) and at 1 week post-discharge. Also collected at baseline was demographic and clinical information related to age, sex, educational level, marital status, co-morbidity, number of grafts received during the CABG procedure (e.g., 1, 2, 3, 4), cultural classification (WE, Indian, Chinese), and cultural generation (first-generation Canadian, second-generation Canadian, etc.). During the baseline data collection period, the data were obtained through questionnaires administered by the research staff. Post-test data were gathered by telephone. One week post-discharge was selected for post-test data collection, as this was the point in time at which immediate changes in self-care behaviour were expected to occur (Fredericks, 2009; Jaarsma et al., 2000; Moore & Dolansky, 2001).

The unit staff were provided with the inclusion criteria and asked to use these in identifying eligible patients. Research assistants then approached eligible patients for possible participation 24 to 48 hours prior to discharge; they used a standardized script to describe the study in detail, answer any questions, and obtain written consent.

Instruments

A standard demographic questionnaire was administered immediately following the securing of consent, 24 to 48 hours pre-discharge. This information related to age (in years), sex (male/female), education (> high school/high school/college/university), marital status (single/widowed/divorced, married/cohabitating), co-morbidity (number of co-morbid conditions), number of grafts received during the CABG procedure (e.g., 1, 2, 3, 4) as reported by the patient, culture (English/Irish/Scottish, Indian, Chinese), and cultural generation (e.g., first-, second-generation Canadian).

Throughout the study, the measurement of cultural relevance was assessed by measuring effectiveness as an indicator of relevance and included an assessment of CABG patient education materials delivered to patients following surgery.

Self-care behaviours were measured 24 to 48 hours pre-discharge and 1 week post-discharge using the Revised Self-Care Behaviour scale (RSCB) (Artinian, Magnan, Sloan, & Lange, 2002). The RSCB is a 29-item self-report, Likert-type scale. The scale describes behaviours that patients with heart failure must perform, to some degree, in order to regulate their own functioning. Thorne and Peterson (1998) identify the immediate post-discharge self-care behaviours performed by heart failure patients as being similar to those of CABG patients. The RSCB was adapted for use in a CABG population, as well to reflect the content of the individualized education intervention (Fredericks, 2009). The behaviours relate to management of post-operative CABG complications, incision and chest pain, nausea, vomiting, fatigue, sleep disturbance, constipation, edema/water retention, and emotional reactions, as well as self-care strategies for medication administration. Respondents were asked to indicate how often they performed each of these behaviours, during the home discharge period, on a scale from "none of the time" (0) to "all of the time" (5) (Artinian et al., 2002). The total score, calculated by summing the scores across items, ranged from 0 to 145. Higher scores indicated more frequent performance of self-care behaviours. Artinian et al. (2002) report the approximate time for scale completion as 10 minutes. Content validity consisted of evaluations by a panel of experts, including two nurse practitioners and two researchers who had investigated self-care in a cardiac population. A content validity index of 0.86 was obtained by Artinian et al. (2002). In addition, the tool demonstrates convergent validity, as evidenced by a positive correlation between a tool for assessing self-care behaviours and the RSCB. As well, an internal consistency reliability coefficient of 0.8 (Cronbach's alpha) was noted.

Analysis

The data were analyzed using both descriptive and inferential statistical techniques. Descriptive statistics (i.e., measures of central tendency and dispersion) were used to characterize the sample on demographic factors and the self-care behaviours performed post-CABG surgery. Independent sample t test was used to identify differences in the mean score on each item of the RSCB related to type of self-care behaviours performed by the WE and non-WE groups. Independent sample t test was also conducted to determine differences between the two groups based on the number of self-care behaviours performed.

Results

A total of 270 patients who met the eligibility criteria were approached to participate in the study. A total of 252 completed the study (for a response rate of 93.3%), with 12 individuals declining to participate due to feeling unwell and 6 indicating that they were not interested after hearing details of the study. The sample was representative of the target population (Table 1).

Even though no questions pertaining to the role of caregivers were asked, anecdotal comments repeatedly emerged to suggest that women routinely took on the role of primary caregiver.

Type of Self-Care Education Received by Participants

The RSCB took approximately 10 minutes to complete. All participants received self-care patient education. This information was presented either orally (by the nurse) (87.5%), in booklet form (98.5%), or on video (38.2%). The majority of participants (75.9%) received self-care information through all three media. There was no statistically significant ($p >$ 0.05) difference between the WE and non-WE cultural groups in terms of the type of self-care education received.

Table 1 ***Demographic and Clinical Data***

Characteristic		%
Age mean *(SD)* in years		63.7 (10.1)
Sex	Male	78.2
	Female	21.8
Highest level of education	< High school	23.5
	High school	20.5
	College	12.5
	University	25.6
Marital status	Single/widowed/ divorced	21.8
	Married/cohabitating	78.2
Generation Canadian	First	43.1
	Second	12.3
	Third	2.5
Culture	English, Irish, Scottish	60.3
	Indian	32.6
	Chinese	7.1
Number of bypasses	1	8.8
	2	32.7
	3	48.1
	> 3	10.4
Number of co-morbid conditions	1	23.9
	2	30.4
	3	20.9
	> 3	24.8
Co-morbid conditions	High blood pressure	96.4
	High cholesterol	82.7
	Diabetes	83.2
	Arthritis	32.5
	Thyroid condition	18.2

Between-Group Differences in Self-Care Behaviours

Of 29 self-care behaviours, 10.1 (*SD* = 1.61) were performed 24 to 48 hours pre-discharge (WE individuals performing 14 on average and non-WE individuals 9 on average), while 15.9 behaviours (*SD* = 9.49) were reported at 1 week post-discharge (WE individuals performing 20 on average and non-WE individuals 13 on average). For WE patients, the behaviours most often performed 24 to 48 hours pre-discharge related to activity and rest, while 1 week post-discharge they tended to be mainly activity-related. For non-WE patients, the behaviours most frequently performed 24 to 48 hours pre-discharge were activity-related, while 1 week post-discharge these individuals also engaged in behaviours related to medication management and nutrition (Table 2).

Between-Group Differences in Type of Self-Care Behaviours

For types of behaviour performed, statistically significant differences were noted in WE and non-WE groups 24 to 48 hours pre-discharge. Non-WE individuals engaged in more activity-based behaviours: use of blue breathing machine (t (260) = 0.00, $p < 0.05$); deep breathing and coughing exercises (t (260) = 0.04, $p < 0.05$); increasing walk time by 1 minute every other day (t (260) = 0.02, $p < 0.05$); not lifting, pushing, or pulling objects heavier than 10 pounds (t (260) = 0.00, $p < 0.05$); and being physically active 3 to 4 days per week (t (260) = 0.01, $p < 0.05$). WE individuals were more likely to adhere to pain management regimens: taking pain medication (t (260) = 0.04, $p < 0.00$); limiting activities that are hard to perform (t (260) = 0.04, $p < 0.01$).

Statistically significant differences were also noted for types of behaviour 1 week post-discharge. WE individuals engaged in more of the following behaviours: avoiding strain (t (260) = 0.00, $p < 0.05$); not lifting, pushing, or pulling objects heavier than 10 pounds (t (260) = 0.00, $p < 0.05$); refilling prescriptions on time (t (260) = 0.04, $p < 0.05$); having a system to help take pills (t (260) = 0.01, $p < 0.05$); taking prescribed pain medication when needed (t (260) = 0.00, $p < 0.05$); contacting the doctor before stopping, starting, or altering pain medication (t (260) = 0.01, $p < 0.05$); spreading activities out over the day (t (260) = 0.02, $p < 0.05$); planning rest times during the day (t (260) = 0.03, $p < 0.05$); not drinking more than 2 cups of fluids per day (t (260) = 0.04, $p < 0.05$); contacting the doctor when feeling tired (t (260) = 0.00, $p < 0.05$); contacting the doctor when nauseated (t (260) = 0.02, $p < 0.05$); and contacting the doctor when having to vomit (t (260) = 0.02, $p < 0.05$).

Between-Group Differences in Number of Self-Care Behaviours

No statistically significant difference between the groups was noted at 24 to 48 hours pre-discharge ($p > 0.05$), but a statistically significant difference was noted at 1 week post-discharge (t (260) = 0.04, $p = .03$), with the WE group performing mean = 15.98 (SD = 9.03) self-care behaviours and the non-WE group performing mean = 10.63 (SD = 10.02) self-care behaviours (Table 3).

Table 2 ***Mean Number of Participants Engaged in Individual Self-Care Behaviours***

	24–48 hours pre-discharge		**1 week post-discharge**	
Self-Care Behaviour	**WE (n = 152) Mean**	**Non-WE (n = 100) Mean**	**WE (n = 152) Mean**	**Non-WE (n = 100) Mean**
1. I use my breathing machine as described by my health-care provider.	59.4	89.5	123.4	83.9
2. I perform my deep breathing and coughing exercises at least 3 times every hour.	29.9	89.5	137.7	88.7
3. I clean all of my surgical incisions every day with soap and water.	0.0	0.0	138.8	93.5
4. I constantly assess all of my incisions for redness, swelling, puffiness, leaks, and tenderness.	4.4	7.4	81.5	70.2
5. I contact my doctor if I notice any redness, swelling, puffiness, leaks, or tenderness.	1.1	0.0	90.3	45.2
6. I contact my doctor when I have abdominal pain.	2.1	1.4	56.2	46.4
7. I increase my walking time by 1 minute every other day, if tolerated.	1.4	89.5	150.3	99.2
8. I try to avoid strain (such as putting weight on upper arms, shoulders, back, neck, and chest).	148.7	99.2	150.9	56.9

9. I use the stairs only when necessary.	3.3	0.8	143.1	94.2
10. I do not lift, push, or pull objects heavier than 10 pounds.	2.1	97.6	150.9	68.4
11. I am physically active (for example, walk) 3 to 4 days per week.	1.8	33.1	148.5	96.4
12. I take my pills every day as the doctor prescribed.	6.5	4.8	149.9	99.2
13. I always refill my prescriptions on time.	1.1	0.0	119.0	54.9
14. I have a system to help tell me when to take my pills.	0.0	0.0	55.0	12.4
15. I take my prescribed pain medications whenever I need them.	58.4	0.0	119.0	52.1
16. I contact my doctor before stopping, starting, or altering my pain medication.	3.6	3.2	104.4	41.9
17. To help reduce my symptoms or fatigue (i.e., feeling tired) or shortness of breath (i.e., having difficulty breathing), I limit the activities that are hard for me.	35.6	93.5	150.2	83.5
18. I spread my activities out over the whole day so I do not get too tired.	143.2	92.7	150.2	62.9
19. I plan rest times during my day.	142.1	93.2	150.2	54.4
20. When I am unable to sleep, I use different techniques to help put me to sleep.	105.8	68.5	92.6	61.9

(cont'd next page)

Table 2 (cont'd)

Self-Care Behaviour	24–48 hours pre-discharge		1 week post-discharge	
	WE (n = 152) Mean	**Non-WE (n = 100) Mean**	**WE (n = 152) Mean**	**Non-WE (n = 100) Mean**
21. I try to eat food high in fibre to prevent constipation.	7.8	2.4	110.0	98.4
22. I weigh myself every day of the week.	4.4	29	131.3	72.4
23. I am careful not to drink more than 2 cups of fluids/day.	39.7	29.4	55.0	24.9
24. I contact my doctor when I have gained 2 pounds or more in a day.	0.0	0.0	56.2	28.1
25. I put my feet up when I sit in a chair if swelling is present in my leg.	56.2	44.4	121.1	62.6
26. I try to return, as best as possible, to my usual daily activities.	55.0	41.1	135.4	96.0
27. I contact my doctor when I feel tired all the time.	0.0	0.0	62.8	12.0
28. I contact my doctor when I have nausea (i.e., sick to the stomach).	1.1	0.0	55.0	2.0
29. I contact my doctor when I have vomiting.	0.0	0.0	54.0	14.1

Table 3 ***Number of Self-Care Behaviours Performed, by Group***

24–48 hours pre-discharge Mean *(SD)*		**1 week post-discharge Mean *(SD)***	
WE	**Non-WE**	**WE**	**Non-WE**
3.70 (1.82)	3.89 (1.61)	15.98 (9.03)	10.63 (10.02)

Discussion

The majority of the non-WE participants self-identified as first-generation Canadians. The generational representation of the sample is significant, as the closer a particular generation is to their country of origin, the more their values, beliefs, and attitudes will reflect those of their homeland (Abouguendia & Noels, 2001). Thus, it is likely that the behaviours performed are a reflection of the behaviours found in the individual's country of origin.

With regard to consistency of beliefs and values of diverse cultures, anecdotal evidence emerged indicating that women were the primary caregivers and that women's main responsibility was to provide care for the family. This finding is consistent with that reported by Salgado de Snyder (1987), who describes the role of immigrant women, according to societal norms, as centred on the needs of the family and the home. Thus, activities pertaining to caring for sick family members are viewed as included in the responsibilities associated with women. The idea of delivering patient education materials to women (i.e., spouse, child, or parent) suggests the need for continued investigation into the appropriateness and feasibility of incorporating female family members into the patient's overall plan of care following CABG surgery. Preliminary findings on the effectiveness of patient education initiatives provided to spouses of patients who have had CABG surgery (Allen, Becker, & Swank, 1991) demonstrate mixed results.

Furthermore, the results suggest that non-WE individuals are engaged in more physical activity and fewer self-care behaviours than WE individuals 1 week following discharge. This finding may be related to employment. Recent statistics indicate that immigrants from China and India form the largest immigrant group in the city of Toronto (Metropolis: Enhancing Policy Through Research, 2009). New immigrants tend to be employed in positions that do not allow for a large number of sick days. Thus, these individuals tend to return to work sooner than their WE counterparts, thereby increasing their likelihood of engaging in long periods of physical activity immediately after hospital discharge.

Implications for Practitioners

This study provides preliminary evidence suggesting that existing self-care patient education initiatives are not culturally relevant. This may be due to a large percentage of the patient population being first-generation Canadians whose approach to self-care is influenced by their specific cultural values (Chachkes & Christ, 1996), as well as existing programs having been developed from a Western point of view. Anecdotal evidence suggests that female family members engage in the caregiver role to support the patient's home recovery. Nurses could consider including family members, in particular the primary caregiver (if this person is available), in patient education sessions. As well, nurses should consider including appropriate recovery time in pre-operative education and screen for those patients who cannot manage this recovery time.

Since a large number of non-WE study participants appear to have been engaged in activity immediately following hospital discharge, it is recommended that nurses work closely with members of the multidisciplinary team (e.g., social workers) to assist patients who are unable to get time off work in negotiating extended recovery periods with their employers and/or accessing appropriate financial resources. Nurses may also wish to stress the importance of minimizing strenuous activity during the first 3 weeks of recovery to promote healing, and thus to work closely with the patient in designing an activity program that will promote healing during work-related activities. Theoretical examination is needed to fully understand the extent to which culture influences caregiving behaviour.

The results from this study indicate a statistically significant difference between WE and non-WE individuals in terms of the number of self-care behaviours performed. Non-WE participants engaged in more work-related activities and fewer self-care behaviours than their WE counterparts immediately following hospital discharge. Continued evaluation to determine the reasons why specific cultural groups engage in specific types of behaviour is needed. In particular, focus groups promoting dialogue on the cultural relevance of existing self-care behaviours are needed.

Limitation

As there was unequal distribution across cultural groups, the groups were collapsed into WE and non-WE clusters. This made it difficult to determine individual variability between specific subgroups. For example, individuals of English, Irish, and Scottish origin were clustered into one group, yet there are subtle differences between each of these cultures that could impact on the relevance of patient education initiatives. Future research could build on this study by using a non-experimental design to determine the cultural relevance of self-care patient education materials currently being delivered following heart surgery. Use of a non-proportional quota sampling design would ensure that specific cultural groups are adequately represented in the sample, and thus allow for a more detailed understanding of the cultural relevance of patient education materials.

Conclusion

The design of current educational initiatives for heart surgery patients is based on feedback received from individuals of Western European origin. This study examined the cultural relevance of these initiatives for individuals of diverse backgrounds. The findings reveal that participants of non-Western European origin engaged in more work-related activities and fewer self-care behaviours than their Western European counterparts 1 week after hospital discharge, indicating a lack of adherence to educational recommendations. This study provides preliminary evidence suggesting that existing self-care educational initiatives may not be culturally relevant. Continued evaluation to determine why specific cultural groups engage in specific types of behaviour is needed.

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Résumé

Partenariats en santé publique : leçons à tirer du transfert de connaissances et de la planification de programme

Shannon Sibbald, Anita Kothari, Debbie Rudman, Maureen Dobbins, Michael Rouse, Nancy Edwards, Dana Gore

Cette étude qualitative visait à comprendre comment s'établissent et s'entretiennent les partenariats dans le domaine de la santé publique. On a mené des entrevues individuelles et des groupes de réflexion. Les participants sont des intervenants actifs au sein de six unités de santé publique de la province canadienne de l'Ontario, choisies à dessein, qui ont établi des collaborations en matière de planification de programme. On a constaté que ces partenariats jouent un rôle essentiel, mais qu'il existe très peu de documentation sur le processus comme tel. La plupart sont établis de façon ponctuelle, sans qu'on cherche à officialiser la démarche. Lorsqu'ils veulent s'associer des partenaires, les professionnels de la santé publique se fient à leurs connaissances expérientielles. Ces conclusions pourraient éclairer la planification en matière de santé publique et renforcer la création et la poursuite de partenariats en ce domaine et dans d'autres sphères. Le fait d'avoir analysé, dans un premier temps, la façon dont les partenariats se créent et s'entretiennent fait ressortir l'utilité de la recherche comme moyen de faire progresser les efforts de collaboration dans le domaine de la santé publique.

Mots clés : santé publique, utilité de la recherche

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Partnerships in Public Health: Lessons From Knowledge Translation and Program Planning

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The purpose of this study was to better understand how partnerships are initiated, maintained, and sustained in public health practice. A qualitative design was employed to conduct individual interviews and focus groups. The participants included practitioners from 6 purposively selected public health units in the Canadian province of Ontario that developed partnerships in program planning. It was found that partnerships play an essential role in program planning but that minimal information is available regarding the partnership process. Most partnerships are formed on an ad hoc basis, with little formalization. Public health professionals rely on their experiential knowledge when seeking out and working with partners. These findings can serve to inform future public health planning and strengthen the formation and maintenance of partnerships in public health and other sectors. Understanding how partnerships are initiated, maintained, and sustained is an important first step in supporting the use of research to advance collaborative public health efforts.

Keywords: collaborative research methods, decision making, nurse relationships/professional issues, nursing roles, public health, research utilization/evidence-based practice

Introduction

Partnerships play a central role in public health care and health promotion and have been acknowledged as an important part of knowledge translation (KT). Partnerships are an essential component of program planning and are often formed between public health professionals and community stakeholders. Through the shifting landscape of public health, partnerships have been reconfigured, tied to changes in practice guidelines, funding mechanisms, and the increasing drive for multisector collaboration. In an effort to make better (research-informed) decisions, many health professionals are recognizing the value of KT and the inherent role of partnerships. In order to ensure effective partnerships in the context of public health, we need to explore what is currently being done to see what does and does not work and to capture some of the benefits and challenges of these types of relationship.

Partnerships are not uncommon in the field of public health. Public health professionals and public health units or health authorities frequently work in partnership with health and health-related agencies around program planning as well as with other key stakeholders (including the community, the media, and researchers). In some jurisdictions, partnerships are legislated. The Canadian province of Ontario, for example, has included partnerships with community stakeholders within the recently established *Ontario Public Health Standards* (Ministry of Health and Long-Term Care, 2008). The government of British Columbia document *A Framework for Core Functions of Public Health* also describes partnerships with community groups as a desirable way of working (Ministry of Health Services, 2005). For our purposes, we have chosen the following definition of community:

> . . . a specific group of people, often living in a defined geographical area, who share a common culture, values and norms and are arranged in a social structure according to relationships that the community has developed over a period of time. . . . They exhibit some awareness of their identity as a group and share common needs and a commitment to meeting them. (Community Health Nurses Association of Canada [CHNAC], 2008, p. 16)

A partnership implies two or more individuals or groups coming together to work for a common outcome or purpose. Partnerships can focus specifically on a health promotion intervention or can be more broad-based and at a higher level.

The KT literature is focused on supporting partnerships between producers and users of knowledge for the purpose of co-creating and sharing knowledge for subsequent action (similar to program planning in public health). In this article we use the KT literature as a lens through which to look at partnerships in public health program planning. The purpose of the article is to examine how public health partnerships are initiated, maintained, and sustained as a first step in supporting the use of research to advance collaborative health promotion efforts.

Background/Literature Review

What Are Public Health and Health Promotion?

Public health has been defined as "the science and art of promoting health, preventing disease, and prolonging life through the organized efforts of society" (World Health Organization [WHO], 2004, p. 141). In order to understand and appreciate the role of partnerships in public health, we must first examine the Canadian primary health care movement in which health care is oriented. Canada's traditional biomedical, curative model of health care was expanded to include preventative (primary health) medicine in the 1970s with the release of the Lalonde Report (Lalonde, 1974). This shift acknowledged that health is shaped by factors beyond the health-care system and that these factors should be addressed in a comprehensive public health framework. Spurred on by the Ottawa Charter in 1986, Canada began to include this reorientation in health care (WHO, 1986). One could easily argue that Canada still has a way to go, given the small expenditures made, both federally and provincially, on preventative care. The Canadian Nurses Association has also moved forward on public health reform by adopting the principles of public health (Calnan & Rodger, 2002). Similarly, the principles have been reflected in standards of specific professions. For example, the *Canadian Community Health Nursing Standards of Practice* (CHNAC, 2008) makes clear the importance of building individual and community capacity in health as a form of empowerment through collaboration.

Health promotion, a central element of public health, has been defined as "the process of enabling people to increase control over, and to improve, their health" (WHO, 1986, p. 1). It has been envisaged as participatory, multisectoral, and focused on tackling the social determinants of health to reduce health inequities (Braveman & Tarimo, 1994). The World Health Organization (1986) sets out five strategies for achieving this goal: building healthy public policy, creating supportive environments, strengthening community actions, developing personal skills, and reorienting health services. The principles of public health influence the organization and operationalization of Canadian health care (Martin, 2006) and are important elements in public health planning.

The Importance of Partnership

Partnerships play a central role in public health as framed by the foundational documents discussed above. Although partnerships are envisaged as egalitarian and empowering (Falk-Rafael, 2001, 2005), the reality of a strong historical orientation towards biomedicine and expert opinion has presented challenges for their realization (Whitehead, 2009). The values that drive public health shape the concept of partnerships in this context, as well as their structure and function within the Canadian health-care system.

Due to its complexity and its multifaceted components, "partnership" is not easily defined. Partnership is a broad and encompassing concept (Sibbald, 2010) and several different partnership types have been identified. For example, MacIntosh and McCormack (2001) classify health partnerships at three levels (sector, discipline, and profession) into three categories. In *multi*-partnerships, individuals work independently to achieve a common goal; these partnerships do not promote equality or active participation and thus are counterproductive to the achievement of public health goals, but rather espouse the expert as decision-maker. In *inter*-partnerships, partners from different domains work together to achieve a common goal. Lastly, *intra*-partnerships consist of partners from the same domain working together towards a common goal.

Many of the partnerships created in the public health context can be described as "academic-practitioner partnerships." These partnerships are essential in maximizing and accelerating the transfer of results from researchers to end users (Nieva et al., 2005) and are a function of enhancing knowledge creation (Bartunek, Trullen, Bonet, & Sauquet, 2003). Other partnerships in public health include community collaborations, which are driven by a need to consider context in collaborations (Eccles, 1996; Lantz, Viruell-Fuentes, Israel, Softley, & Guzman, 2001; McHale & Lerner, 1996). Also, there is a growing body of literature on health-care networks that encompass a broader conceptualization of partnering (Cobb, Graham, & Abrams, 2010; MacLeod, Dosman, Kulig, & Medves, 2007). Most definitions agree on two key dimensions of partnership: inter- or multidisciplinarity, and a shared goal (Amabile et al., 2001; Jassawalla & Sashittal, 1998; LeGris et al., 2000; Walter, Davies, & Nutley, 2003).

It is important to note that this definition implies that partnerships involve different disciplines and are thus professional in nature, which excludes individuals and communities as active partners in health and conflicts with the principles of public health care. We believe that public health partnerships are broader. We support the Community Health Nurses Association of Canada definition of partnerships:

> . . . relationships between individuals, groups or organizations where the different participants in the relationship work together to achieve shared goals. Partnership involves active and flexible collaboration between health care providers and clients, individuals and communities, includes choice, accountability, dignity and respect, and focuses on increasing clients' capacities for self-reliance using empowering strategies. (CHNAC, 2008, p. 17)

As well as being powerful tools for putting public health principles into action and for contributing to individual and community empowerment, partnerships are thought to lead to positive outcomes, including the use of research in decision-making (Denis & Lomas, 2003; Lavis, Lomas, Hamid, & Sewankambo, 2006; Ross, Lavis, Rodriguez, Woodside, & Denis, 2003). It has been argued that collaboration strengthens decision-making (Amabile et al., 2001) and improves planning and delivery processes (Denis & Lomas, 2003; Kitson & Bisby, 2008; Kothari, McLean, & Edwards, 2009). Partnering also allows for unique and informed perspectives on design (of research and/or programs) and ensures that the end product is relevant to users (Bartunek et al., 2003; Ferlie & Wood, 2003; Goering, Butterill, Jacobson, & Sturtevant, 2003; Innvaer, Vist, Trommald, & Oxman, 2002). Partnering early on in the planning process serves to increase ownership and use of results (Elliott & Popay, 2000; Kothari, Birch, & Charles, 2005; Lavis, Robertson, Woodside, McLeod, & Abelson, 2003). Scott and Thurston (1997) identify clear agreement over the sphere of interest (or the domain of the partnership) and high levels of communication as essential to a successful partnership.

Support for Partnerships at the Local, National, and International Level

The broad nature of the social determinants of health makes partnerships between sectors such as agriculture, food, housing, and education indispensable to improved health outcomes. At the local level, there is a need for community participation at all stages of care (e.g., planning, organization, and delivery) as well as for partnerships between health professionals and communities. There is support for the use of partnerships at the local, national, and international level. A number of the central tenets of the Ottawa Charter — for example, developing public health policy and strengthening community action — inherently require partnerships, as they cannot be fulfilled by any one group (Catford, 2004). Coordinated action and international partnerships (including those between governments, health sectors and other sectors, NGOs, local authorities, the media, communities, families, and individuals) are encouraged as way to ensure public health for all (WHO, 1978, 1986). For our purposes here, we have adopted the CHNAC (2008) definition of "community" (presented above, in the Introduction).

Partnerships between sectors, population groups, and civil society are also viewed as a central feature of any health-care system that is oriented towards reducing health inequities. As public health and health promotion practice has evolved since the 1980s, the need for complex, multisectoral, egalitarian partnerships has been reinforced in documents such as the Galway Consensus, the Jakarta Declaration, and the Bangkok Charter for Health Promotion (Allegrante, Barry, Auld, Lamarre, & Taub, 2009; WHO, 1997, 2005). Further, there is research to support the notion that partnerships are more successful when they are participatory and egalitarian (Cargo & Mercer, 2008; Gillies, 1998; MacIntosh & McCormack, 2001; Scott & Thurston, 1997).

Partnerships in the Context of Knowledge Translation

In the KT literature, relationships are identified as a key ingredient in effective KT. Recently the KT literature began to spotlight partnerships as an essential feature of effective KT. Authentic two-way knowledge transfer and utilization is much more likely to take place in partnership relationships (Jansson, Benoit, Casey, Phillips, & Burns, 2009). Partnering also allows for unique and informed perspectives on KT (Bowen, Martens, & Crockett, 2005; Jansson et al., 2009; Ross et al., 2003). In addition, partnerships provide mutual learning opportunities for decision-makers (Bartunek et al., 2003) and researchers (Denis & Lomas, 2003; Rynes, Bartunek, & Daft, 2001) and often lead to the development of new skills (or "spin-off" benefits), which can affect knowledge production and the transformation of practices or modes of intervention (Denis, Lehoux, Hivon, & Champagne, 2003; Kothari et al., 2009).

Pablos-Mendez and Shademani (2006) hold that "the dynamic interaction of people who come together to solve public health problems, to learn, and ultimately to drive productive change" (p. 81) is a key feature of KT. The Canadian Institutes of Health Research has coined the term "integrated knowledge translation" to capture the new, more collaborative way of engaging knowledge creators (researchers) and potential knowledge users (Graham, Tetroe, & Gagnon, 2009). Application of the term "knowledge creator" to researchers and "knowledge users" to other partners has been challenged in other conceptualizations of KT, which reject the traditional "research to practice" model in favour of more community-centred participatory models (Cargo & Mercer, 2008; Flaspohler, Duffy, Wandersman, Stillman, & Maras, 2008). This is part of the evolution of KT to better fit the principles of public health, which are meant to build community capacity, empower individuals, and ultimately increase one's control over the health and well-being process. Some participatory-based strategies taken up with KT include community-based participatory research, participatory action research, participatory rural appraisal, and empowerment evaluation. These approaches are meant to democratize the knowledge-production process and increase community empowerment and ownership with respect to results and, in turn, health and well-being (Cargo & Mercer, 2008).

The work presented in this article is one component of a larger study (Kothari et al., 2010a, 2010b) whose objective was to describe patterns of knowledge exchange for program planning, with a focus on tacit knowledge. The area of partnerships emerged as a major theme in this work and is described here. The purpose of this article is to examine how public health partnerships are initiated, maintained, and sustained as a first step in supporting the use of research to advance collaborative health promotion efforts.

Methods

Design

The data collected for and analyzed in this article come from a narrative inquiry intended to describe patterns of knowledge exchange among public health professionals and their various partners in program planning. We framed the study as what Lieblich, Tuval-Mashiach, and Zilber (1998) describe as a holistic, content approach to narrative analysis — where the focus is on drawing out themes related to content areas addressed in the narratives. Eliciting knowledge embedded in routine practice can be challenging given that such knowledge is difficult to articulate. We adopted Ambrosini and Bowman's (2001) two-step method involving individual narrative interviews followed by a focus group at each site.

This article examines in depth the partnership types, processes, and challenges experienced by our participants, which emerged as a major theme in the study. The narrative inquiry design allowed us to explore both the sequence of the partnering events (i.e., when the partnership was formed, what precipitated it, and what the role and function of the relationship were) and the consequences of those events (Riessman & Quinney, 2005). In narrative inquiry, participants are encouraged to tell their stories of what transpired. These stories are constructive as well as reflective (Chase, 2005; Clandinin & Connelly, 2000).

Setting and Sample

A multi-stage sampling process was used. The first stage was to sample public health units (PHUs). The province of Ontario has 36 PHUs. We purposively sampled along two dimensions: PHU teams, and the topic area(s) in which the planning teams worked. PHU teams were purposively selected (*n* = 6). Recruitment of the teams was done through PHU directors, as per ethics requirements. Directors were given an information letter detailing the project's goals and the amount of involvement of their staff. Teams were included if they were currently planning a program/intervention or had planned one in the preceding 6 months. In order to allow for maximum variation, selection was based on geographic location and academic affiliation. To reduce participant burden, PHUs that were already engaged with any of the authors in other KT research projects were not asked to participate in this study. Wherever possible, individual interviews were conducted with all members of the PHU team. Participants could take part in both a focus group and an individual interview.

Data Collection

Data collection took place between September 2007 and December 2008. Individual semi-structured interviews, designed to elicit participants' narratives about the planning initiative, were conducted. These were followed by focus group discussions aimed at drawing collective narrative maps of the planning initiative (according to Bruner's [1991] collective representation). These narrative map sessions started with a broad question (e.g., *Tell me about the initiative you recently planned*) in order to uncover the underlying knowledge informing program decisions. Of particular relevance to findings pertaining to partnership, this mapping also led to discussion of the various players involved in an initiative and their working relationships with each other. Maps were used as a focus group discussion tool, not as a source of data. All interviews and focus groups were audiorecorded and transcribed verbatim. Focus groups are very useful because they allow the participants to be an active part of the process, enabling the creation of group experiences (Kitzinger, 1995). Having individual interviews in addition to focus groups gave participants an opportunity to speak more freely and thus mitigated any power imbalance that may have occurred during the focus group.

Data Analysis

Individual interviews were analyzed first to elicit a deeper understanding of how teams accessed, made sense of, and used various types of information and knowledge (we asked them about typical planning processes, challenges faced, and strategies used in planning). Qualitative coding of the interviews was carried out separately by two members of the research team using a coding scheme similar to that used for the focus groups; codes were added or removed to fully capture the nuanced differences between the group and individual discussions. For the purposes of this article, we also selectively coded for content dealing with partnerships — how they were formed, challenges in their creation and maintenance, and any indicators of successful partnering.

Focus group data were analyzed next. The nine focus groups brought together planning team members, both within the same PHU and from PHUs in the same region, to think about the recent common initiative in whose planning they were involved and to describe all the steps (e.g., How does it happen? What are the influences? Is this typical?). Focus group data were analyzed by at least two independent researchers. A coding scheme was created inductively from the transcripts and then iteratively used to analyze all focus group data — that is, the coding scheme emerged from the data. We employed a holistic, content approach to identify the main content areas addressed in the narratives and the identified themes related to how these content areas were discussed.

We selectively coded for (1) types of knowledge, or how knowledge was being used in program planning; and (2) the role and function of partnerships in program planning. Our study focuses more on the latter; for a description of some of the other findings, see Kothari et al. (2010a). From the focus group transcripts, narratives were created; these identified the key constructs (events, people, and places) commonly described by participants.

The results presented below include both the focus group (team) and the individual analysis in aggregate. Anonymized verbatim quotes are provided to illustrate our findings from the participants' viewpoint. (Focus group participants are denoted by "FG," interview participants by "I.")

Ethical approval for the study was granted by the Health Service Research Ethics Board of the university.

Results

First we present a description of our participants. This is followed by a description of the rationale behind partnering and the process used to initiate programs and partnerships. We present the different types of partnership discussed by our participants and finish by discussing the challenges encountered in maintaining and sustaining partnerships.

Participants and Programs

In total, 24 individuals participated in one-on-one interviews and 47 participated in focus groups (see Table 1).

Participants discussed programs that were at different phases of development. Some programs had yet to be fully operationalized (planning

Table 1 ***Sample: Individual Interviews, Focus Groups, and Focus Group Participants***

Site	**Individual Interviews (*n*)**	**Focus Groups (*n*)**	**Focus Group Participants (*n*)**
A	6	2	6
B	4	3	14
C	5	2	12
D	9	2	15
Total	24	9	47

phase), some were currently running (operational phase), and some had already been implemented (complete). Programs spanned several chronic health issues, including tobacco/smoking cessation, diabetes programming, cancer screening (for women), and healthy eating/obesity strategy. The majority of participants were women between the ages of 18 and 59. Most participants had a nursing background (71.4%, *n* = 15) and were public health nurses (61.9%, *n* = 13). Other participants included a Local Health Integration Network Consultant (4.8%, *n* = 1); a Public Health Dietitian (9.5%, *n* = 2); a Public Health Nutritionist (4.8%, *n* = 1); a Tobacco Control Coordinator (4.8%, *n* = 1); and a Health Promoter (14.3%, *n* = 3). Over 50% (*n* = 12) of participants had 1 to 9 years of service in public health; only one participant had been in public health for more than 30 years (participant demographics are available upon request).

Why Partnerships?

Partnerships emerged as an especially important element associated with both forming a program planning team and choosing which program to plan, as well as specific program details. Most PHUs drew upon the skills and professional expertise of their own staff. Therefore, planning teams were made up of both novices and individuals who had experience with a similar program or in a certain field, providing a mix of new (or textbook) knowledge and experiential knowledge. Discussion on forming/using partnerships often began at the start of program planning.

While partnerships were seen as beneficial for many reasons, participants listed three overarching benefits: (1) providing new/additional resources (time, personnel, and funding); (2) providing fresh ideas; and (3) providing an "in" within the community. Participants frequently described their reliance on experiential knowledge of community needs and prior experience with relevant programs in determining the best program to pursue. This was true of both the knowledge of public health professionals and the knowledge of the partners. Previous experience with community partners also guided collaboration with partners for new initiatives:

> *There are two community room[s] [in the grocery stores] here in the city. One is highly organized and the [other] is less so. We go to the highly organized one, and they just — if anything urgent goes wrong we would have instant correction . . . instant help, and so I trust that . . . [because] I have worked with them before.* (FG)

Decisions on how to proceed with program planning were based primarily on professional experience (i.e., what has been done before, what has and has not worked) and secondarily on other forms of information (such as grey and academic literature, conference/workshop presentations, and information obtained from electronic mailing lists). When working with partners, participants strongly believed that program planning decisions should be (and were) made through group consensus. The strong acceptance of and need for consensus seemed to drive program planning and the development of partnerships in all of the units we studied.

Types of Partnership in Public Health

Once a planning team had been established and a program decided upon, the participants often found that forming formal partnerships was critical to the planning and implementation of the program. Identifying partnership as an important factor was sometimes explicit (e.g., "Someone said we need to get partners") but more often implicit (e.g., the planning team "just knew" that finding partners was an essential step in the program's success).

Three types of partnership were discussed by our participants: (1) partnerships internal to the PHU (outside the planning team but internal to the unit); (2) partnerships internal to public health (outside the unit, with public health professionals from other units); and (3) external partnerships (external to both the unit and public health). These partnerships were formed for different reasons and participants were not always able to explain why they chose to partner with particular groups or individuals. Participants often relied on experiential knowledge when making partnership decisions.

Partnerships internal to the PHU. Participants in the focus groups and interviews had regularly partnered with colleagues outside of the planning team and internal to the PHU. This strong tendency to reach out to experts within their own unit was common to every unit. Several participants described the physical work environment as a key enabler of these partnerships: shared work space, common lounge/eating area, and small offices. All of these factors made conversations with colleagues a regular occurrence. Participants also felt that these kinds of partnership were part of the culture of their PHU. There was little discussion about whether this was a phenomenon of public health as a whole, but many participants agreed that their own unit supported collaborative partnerships.

Partnerships with other public health professionals or other PHUs. Partnerships with other professionals or units were used at different stages in program planning but always with the attitude of making the most of available resources (time, people, and money). When asked why a planning group chose to partner with a neighbouring health unit, one participant replied, "We [want to] enhance what's already happening and . . . give something to everybody that they want and need." (FG)

Participants commonly talked about getting program ideas from other professionals through electronic communication and resources (i.e., using information obtained through electronic mailing lists or Web sites). While these are not direct partnerships per se, there were several examples given of more formalized partnerships (with units where the initial idea had come from) developing once program planning had commenced:

> *That's why we tend to partner up with someone like [nurse from another unit], who has a program she wants to deliver, a specific health enhancement program. We've got facilities but we haven't got any program staff.* (FG)

This piggybacking with other, larger programs, or with smaller programs in other health units, was often used in order to maximize limited resources (due to lack of funding). Participants were aware of these other programs based on their experience.

Participants also talked about the recent trend towards mandated partnerships external to the unit. These partnerships were often less dependent on prior knowledge and more dependent on explicit forms of knowledge (i.e., knowledge that frequently is codified [written] and communicated through language). While most of the programs discussed in this study were created internal to the unit, there was much discussion around the shift towards provincially mandated or required partnerships (i.e., a top-down approach). One example given was mandated connections (partnerships) between public health teams and regional health planning bodies (in Ontario, these are known as Local Health Integration Networks, or LHINs) by the provincial nursing association:

> *The proposal was to strengthen the role of the health unit, working with the LHIN because of the political funding . . . this was a way of working together . . . we know the people at the LHIN — they call us, we call them, . . . it was a pilot and the pilot was the dyad between the health unit and the LHIN.* (I)

Often, mandated partnerships meant dedicated funding. However, participants felt that it made partnering more methodical and less grassroots (i.e., less bottom-up) and somewhat counter to the types of planning and implementation with which they were familiar. This was accompanied by confusion about the specific roles of the partners (LHINs versus PHUs).

Another important partnership with "professionals" was that with *researchers.* Unless researchers were formally affiliated with/linked to the PHU, partnering with researchers on programs was limited. The planning team included researchers only when the health unit as a whole had a larger plan to include researchers on the team (i.e., it was not the planning team's decision). This was most commonly for the purposes of evaluation. The duration and level of involvement of the researcher varied. For example, one unit had a researcher/evaluator on the program planning team from the design phase (i.e., at baseline), while another unit had a researcher/evaluator join in at the end to perform a summative evaluation.

Participants also talked about relationships with researchers external to the PHU, with local universities or colleges. These partnerships were used at different stages in the planning process. A few of the PHUs had formal and ongoing partnerships with universities and researchers, but this was not the norm. Participants often sought support from university researchers when they needed research literature they could not access themselves:

> *If [we] need something, then I can do that. There are a couple of people . . . one teaches part-time at [the university] and so she has access to that as well, so . . . we certainly take advantage of opportunities like that, and we're good about sharing that. It would be nice to have a more formal process in place to access [information].* (I)

There was a similar discussion in a few of our focus groups about the use of academic reports (such as literature reviews, theses, and presentations) in program planning. One group, for example, used the literature review section of a report to support its decision to include more stakeholder discussions in program planning.

External partnerships. The most common form of external partnership was *community partnership;* nearly all focus groups and interviewees highlighted the importance of partnering with the community, such that community partnering was essentially a "natural" part of program planning. Participants felt that collaboration with members of the target community was an important way to draw on experiential knowledge in the community as well as to access knowledge not easily obtainable from written sources (for example, the cultural perspective).

These partnerships provided opportunities for two-way co-creation of knowledge with individuals outside of the immediate team, as a way to adapt planning ideas to local realities.

Planning teams that had strong relationships with their community at a unit level had less difficulty partnering with community stakeholders and building on existing community partnerships. This was often attributed to the development of trust, which took both time and "insider know-how." There was also agreement that partnering with the community fostered trust-building in the community, which our participants felt was vital to the success of any public health program:

> *I've learned that it takes so long . . . it's taken years to say, well, I can walk into a different community, but if I betray the trust of that community I can never go back again . . . because unless you have an inside person who is trusted . . . working with you, it doesn't work, and that's something I've learned.* (FG)

Partnering with the community also had its challenges, one example being lack of engagement by the community. One health unit discussed its community's lack of engagement despite efforts on behalf of the unit to get the community involved. Participants also discussed geography as a challenge to community partnerships — this was especially true for units that served several communities spread over a large geographic area. For example, one unit that served many different communities in a large geographic region found it difficult to reach certain remote target communities.

Another important external partnership was *media partnerships.* Participants considered the media an extremely important and valuable partner in public health programs. Long-term relationships with radio and print media were the most common form of media partnership, followed by television. These relationships were very beneficial for the units. Participants acknowledged the importance of matching media campaigns with the specific needs of the community and the area — for example, reaching individuals in rural towns. One health unit spoke highly of using the local arena to promote its programs. This was especially true for province-wide initiatives — participants believed that their own knowledge of what does and does not work in their community was more valuable than a "one size fits all" media approach:

> *It appears that the ministry is . . . really gung-ho at implementing campaigns, mass media campaigns, because they do want to reach a lot of people, . . . campaigns are . . . valuable but only to a certain degree . . . and for some people . . . not enough to make them change their behaviour . . . especially at the regional level.* (I)

A third type of external partnership was with *other non-health organizations.* These partnerships were often strategic, such as to attract the attention of the public or of funding agencies:

> *Our advocacy role, of course, is paramount, so when . . . you've got the Canadian Cancer Society voice behind something that you're trying to pass municipally, provincially, or federally, that can make an impact, and so that's sort of our perspective . . . [partnering] is very important.* (FG)

Participants also cited the securing of full-time funding, with the aim of handing off the program to the partner, as another strategic reason for forming partnerships. This approach frees up the resources of the PHU while ensuring that the program is still available to the community. One example given by a focus group was a children's program to promote a healthy and active lifestyle:

> *We don't run it, but we're in partnership with [name of children's centre], with the YMCA, with the board of health . . . it's a group of people who all recognize that there's a program that needs to be delivered in the community. . . . it's not any one of us that's really taking the lead, we're all — we recognize there's a benefit to working together on these things.* (FG)

There was also discussion, in a few of the interviews and focus groups, about "non-traditional" media partnerships for the purpose of program promotion. The partners in these cases included restaurants, stores, hockey arenas and community centres. Participants agreed that making the community aware of the program was the priority, and they chose partners who would help them to meet that goal by getting the word out.

Maintaining and Sustaining Partnerships

Our participants described a successful partnership as one in which a variety of partners come together with public health professionals and both groups see the program and the partnership as important:

> *When we first thought of [the program], we started with just a few heads around the table at the health unit, and knowing that this seemed to be very successful in our [other] office, but successful from the point of view that there were other interested partners that were willing to help make these programs . . .* (I)

Participants spoke of several challenges and issues in developing, maintaining, and sustaining partnerships. They acknowledged that it takes time to build and develop trusting partnerships. Four major challenges were discussed: conflicting ideas, proximity, turnover, and funding.

Conflicting ideas (about how to run the program or about appropriate outcomes) was frequently mentioned as the reason for a partnership's failure. One participant said, "Just because an agency had said they would partner with you does not guarantee that they would stick with you." Another group elaborated on this challenge:

> *Our partners often don't share the same viewpoint when it comes to evidence. They don't have to care about it so they don't want to care about it . . . so you do it because you don't want to lose them as a partner and you*

> *know they'll walk if we toe a real hard line. So I feel like we're always [tied] and trying to figure out where the balance is, and sometimes you get it and sometimes you don't.* (I)

Proximity. An important factor in developing and using partnerships in program planning was how close partners were located geographically. The partnerships described often entailed proximal and familiar partners; both community and academic teams that were geographically close to their partners tended to pull expertise and knowledge from them more frequently and with greater ease:

> *I think we're really fortunate due to our geography and in our population that we end up working really collaboratively together. There's not a lot of time spent having to get to know the partners, because it's always the same people around the table, and so you can really get a lot done.* (I)

The ability to have face-to-face meetings was seen as a "huge advantage" in getting partners on board. Some of our participants expressed ease in forming partnerships (and connections) with agencies and community groups due to the small size and cohesiveness of the community. A sizeable distance between the planning team and the program's partners was seen as a challenge to the effectiveness of both the program and the partnership.

Turnover. Another challenge to creating successful partnerships was turnover in partnering organizations. A few units described having a hard time forming partnerships, since "all of the players don't necessarily know each other from past projects." Staff who were new to the partnership (non-PHU) did not always understand existing partnerships, the historical investment behind them, or their function. Participants saw this as a challenge to effective partnerships:

> *When you're in partnerships and . . . somebody . . . just happens to [be in] that position and doesn't understand the role of public health, that can be a challenge in and of itself. They don't understand how a health unit works, why you're doing what you're doing, and some of the other partnerships that they don't understand why we're a part of.* (I)

The same could be true for staff of the health unit, where building trust in partnerships was a challenge; participants described this as an issue not of turnover but of new staff coming on board:

> *It's the trust. If you betray the trust of the community they'll never come back to you . . . people assume you're the leaders of the community . . . it's the trust part of it . . . every time a new person comes on . . . they're think-*

> *ing, we send this person into the community and it will all get done. You won't get anywhere with the community unless it's a trusted individual.* (FG)

Funding. Many of our participants talked about challenges associated with partnering and funding. Funding to run programs was often difficult to find, and even with partnerships the funding was not always guaranteed or consistent. There was also some discussion about the dearth of funding available to public health programs and the challenges of working within limited funding pots:

> *Some money pots are trickier than others. They then took our program . . . we piloted it and they took it on . . . and we got no credit whatsoever . . . we don't even access that funding pot now . . . forget that and we go on to other sources.* (FG)

This difficulty in locating and securing funding made partnering even more of a necessity. Despite the challenges inherent in partnering, partnership was often a way to improve funding or to gain access to program funds.

Although the challenges discussed by our participants were significant, overall they believed that these were outweighed by the benefits of partnering. They gave examples of successful long-term partnerships as reasons for working through the initial challenges. One group spoke of its media partnership as essential to the program's success. Another group spoke of the invaluable link with the larger provincial network in bringing ideas to fruition.

Discussion

Perceptions About Usefulness of Partnerships in Public Health

We know from the literature that early and ongoing engagement of partners of any sort is essential to ensuring uptake and buy-in (Lomas, 2000; Martens & Roos, 2005). This is certainly true for public health initiatives: the earlier that partners are engaged, the more likely they are to stay involved and to support the programs that are delivered (Lencucha, Kothari, & Hamel, 2010). This is particularly important in public health, where the success of so many programs depends on public involvement — without the participation of "key" partners, the program might not survive. Partnerships are formed with communities, media groups, academic centres, other health professionals, and health units.

While our participants did not always explicitly acknowledge the role of partnerships with other health units in their own planning, it was evident in both focus groups and individual interviews that other professionals (most notably researchers) played a role in program planning.

Partnerships were described as either required (e.g., mandated) or inspired (e.g., grassroots) in origin. Formal guidelines (and often accompanying funding opportunities) seemed to make partnering confusing and less organic for planning teams (especially in determining partner role and function). However, this did not necessarily mean that the partnership would be more or less successful (either for the public health professional or for the target community).

Several key findings from this study help us to better understand the function of partnering in public health. Planning teams consisted of individuals with wide experience; team members ranged from experts to newcomers in the field. This intentional mix was seen as both a teaching tool for experts (which supports the results of similar research [Denis & Lomas, 2003; Rynes et al., 2001]) and a learning experience for novices (Bartunek et al., 2003). Our findings are consistent with the public health trend towards group consensus in decision-making. However, we now have a deeper understanding as well as evidence showing that decisions are often based on experience (i.e., what has been done before) rather than on explicit knowledge (e.g., grey and academic literature, conference/workshop presentations, and information from electronic mailing lists). Generally, our findings conform with those of Rycroft-Malone et al. (2004), who developed a taxonomy of knowledge sources, including research, professional knowledge/clinical practice, local information, and patient experiences/preferences, and those of Estabrooks et al. (2005), who found that nurses frequently privileged experiential knowledge over more traditional formal sources (i.e., books, journals). Similarly, decisions on when and who to partner with in public health initiatives are largely based on experience with the partner and the community.

Impact of Partnerships on Program Planning

There was widespread agreement that partnerships are essential to the provision of effective and comprehensive public health initiatives. Despite some of the issues and challenges faced, most groups reported positive partnership experiences. These positive experiences were attributed to the existence of strong community relationships, opportunities for collaboration, defined roles within the partnerships (in the case of both formal and informal partnerships), and tools (or forums) for communicating and sharing information at every stage of program planning (electronic mailing lists, Web sites, etc.), all of which are important in establishing channels of communication and keeping them open. Our findings are supported by the work of Bowen et al. (2005) and Goering et al. (2003), who describe components (or enablers) of effective partnering.

Barriers to and Facilitators of Partnering

Partnerships are not easy to develop and maintain. They are time-consuming and can be accompanied by conflicting ideas (about how to run the program or about the appropriate program outcomes). Further, turnover in partnering organizations often results in loss of knowledge with respect to the partnership, the historical investment behind it, and how it functions. Our participants saw turnover as a major challenge in creating partnerships. This reinforces the idea that partnerships work best when members know each other in advance. Some authors report more favourable outcomes when the partners were previously known to each other (Denis et al., 2003). However, it is also important to work with new (unknown) partners, in which case time for partnership development and relationship-building is critical so that the type of expertise needed will be available. Recall that favourable outcomes can occur both when the partners are known to each other in advance (Denis & Lomas, 2003) and when they are not (Golden-Biddle et al., 2003).

In our study, close geographic proximity to other stakeholders and previous relationships with stakeholders (for example, with a small community) were facilitators in forming partnerships. This finding corroborates the previously cited finding in the literature related to the effectiveness of partnerships in which the partners are known to each other (Denis et al., 2003). In the present study, smaller communities, which also self-identified as cohesive, had an easier time establishing ties with partners.

Not surprisingly, the solutions to challenges suggested by our participants are in line with the findings reported in the literature. For example, units that had more face-to-face interaction tended to self-report more successful planning and implementation processes (Innvaer et al., 2002). Kothari et al. (2005) hold that increased interaction leads to informal, longer-term partnerships between the researcher and the end user.

Lessons Learned

Collaboration with the target community was important for sharing experiential knowledge as well as for providing program planners with important community knowledge. Moreover, co-creating knowledge through discussion with community partners allowed teams to adapt planning ideas to their current reality and context (an important success factor in program implementation). This suggests that public health professionals need to take the time to build trust within the community, in order to ensure program success. It is evident from our findings that long-term partnerships are highly valued and are regularly used in program planning and implementation. Research has shown that such long-term collaborations can offer important learning opportunities, which in turn can effect significant organizational and cultural changes (Denis & Lomas, 2003). As partnerships develop into "more effective and institutionalized relationships, one should expect a gradual shift in emphasis within the partnership work, from being activity-driven to becoming more strategic, looking and planning for opportunities to yield synergistic rewards" (Brinkerhoff, 2002, p. 220).

The findings show that relationships with partners can be either mandated or ad hoc, but most often public health professionals experience the latter, where seeking and forming partnerships is part of the process. While there are advantages and disadvantages to both approaches, we acknowledge the benefits of formalizing both the partnership itself and the partnership process in order to better capture best practices in partnering and to develop a repertoire of sustainable partnerships. A challenge faced by many public health professionals is the time it takes to build relationships and the trust needed to sustain those relationships.

Strengths and Limitations

This study was carried out using only a small sample of PHUs in Ontario, Canada. The intention was not to produce results generalizable to other health units, but rather to gain insights into the various ways that knowledge is used by public health professionals within processes of public health program planning. While partner agencies were invited to take part in the focus group sessions, they were not well represented in our discussions. Partners might have a different perspective on partnering with PHUs, which could be explored further in future research in order to examine the intricacies of partnerships from the perspective of both partners.

Although many focus groups and individuals discussed the importance of long-lasting partnerships, there was very little discussion by the groups around how to actually achieve enduring partnerships. This is another area that merits further investigation.

Conclusion

Our results provide some insights into partnerships as a way to advance health promotion. It is clear that partnerships play a key role in health promotion and public health planning. Health promoting strategies are developed in collaboration with health agencies and community-based organizations from multiple sectors. The findings point to a strong reliance on experiential knowledge for determining partnership membership, while geographic proximity and mandates for collaboration acted as catalysts for partnership momentum and success. Challenges to partnerships conformed to those similarly identified in the KT literature. This understanding of the intricacies of partnership processes provides an access point to the introduction of evidence-informed decision-making for collaborative health promotion programs.

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