

The psychosocial needs of students conducting research with patients and their families in advanced cancer and palliative care: A scoping review

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ABSTRACT

Objective: The objective of this article was to explore the extent of the scientific literature and evidence base about the psychosocial needs of students conducting research in the fields of advanced cancer and palliative care.

Method: A scoping review was conducted in major scientific databases. English-language articles on the topic of interest were retained if they were published in peer-reviewed journals between 1995 and 2013.

Results: A total of 3,161 references were screened, and 7 were retained for analysis. Only two articles were empirical studies involving the collection of primary empirical data. The remaining ones were commentaries and personal reflections. While there is a near absence of empirical research about the psychosocial needs of students, several commentaries suggest that students in this field have a high need for support. Three themes were identified in the limited literature retrieved: (1) the importance of proper training and supervision; (2) the availability of emotional support structures; and (3) the use of effective and deliberate self-care strategies.

Significance of results: This scoping review demonstrates that little is known about the psychosocial needs of students conducting research in advanced cancer and palliative care. However, what is clear is that there is a large emotional impact on student researchers engaged in this type of work. Adequate training and support is needed to promote students' health and well-being, encourage retention of students, and foster high-quality studies. More empirical data are needed to better understand the experiences of students conducting this type of research and to ensure the sustainability of training and research in this field.

KEYWORDS: Psychosocial needs, Students, Research, Cancer, Palliative care

INTRODUCTION

Patients suffering from advanced cancer and their families face highly charged emotional and challenging moments. Conducting research with this patient popu-

lation can be a very personally demanding endeavor. While scholars have explored the methodological and ethical concerns inherent to research involving this vulnerable population (Koenig et al., 2003; Emanuel et al., 2004), this work has so far been largely dedicated to addressing the impact of such inquiry on study participants rather than the researchers themselves.

Among sensitive topics, conducting research in the field of advanced cancer or palliative care can pose

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particular emotional challenges for researchers. Cancer is a common and greatly feared disease with important consequences for quality of life and life expectancy. As such, researchers may readily identify with the experiences of human pain and suffering associated with life-threatening illnesses. Moreover, we can expect that students conducting research in this area may be at even greater risk given their lack of experience as novice researchers and the added contextual stressors of being a student.

The research question guiding this scoping review emerged from the experiences of students conducting advanced cancer or palliative care research. The Palliative Care Student Group (PCSG) was initiated through an interdisciplinary collaboration of students in Montreal, Quebec, Canada. This independent group was born of students' personal experiences of feeling isolated and emotionally distressed and needing better support during their doctoral studies. The PCSG was developed to offer a formalized source of support for students conducting research in advanced cancer and palliative care, and it has continued to grow in membership and function since its inception. While the PCSG executive committee continues to be comprised of students from the Montreal area, the membership represents students from around the globe. As part of its activities, the PCSG hosted the inaugural Student Section at the 2010 International Congress on Palliative Care with the aim of bringing together graduate students and postdoctoral fellows from any discipline with an interest in palliative and end-of-life care to network, share, learn, and find support. The feedback from student attendees was reminiscent of the experiences that had brought about the creation of the PCSG and further confirmed the need to build better support for students doing research in the field. The following research question underlying this scoping review represents the first empirical step in developing this support: "What is known about the psychosocial needs of students conducting research with patients and their families in advanced cancer and palliative care?"

METHODS

A scoping literature review was conducted to explore the extent of the scientific literature and evidence base about the psychosocial issues that students face when conducting research in the fields of palliative care and/or advanced cancer (Arksey & O'Malley, 2007; Anderson et al., 2008; Levac et al., 2010). This methodology permitted charting the available scholarship to assess the breadth of existing research, in a descriptive and visual report, while highlighting the implications for future research and policy development (Davis et al., 2009; Armstrong

et al., 2011). This manuscript is a scoping review and therefore does not involve the collection of any original data. The studies screened and reviewed are publicly available in scientific databases.

Search Strategy

The search strategy and data extraction followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009). The PRISMA guidelines provide explicit methods to identify, select, and critically appraise relevant studies related to a research question. The Medline, PsychInfo, CINAHL, and SocINDEX databases were searched with selected keywords in the title or abstract of articles written from 1995 to 2013. The keywords used were: researcher* OR graduate student*; psycho* OR need* OR support* OR stress; cancer OR palliative OR hospice* OR end-of-life OR "end of life" OR sensitive OR life-limiting OR life-threatening OR terminal* and ill* (where * indicates truncation). The database searches were limited to peer-reviewed articles written in English. Snowballing searches were conducted in the reference lists of selected articles, in Web of Science, and in Google Scholar.

Selection of Literature

The inclusion criteria were: articles written in English and published in a peer-reviewed journal between January of 1995 and December of 2013. The research questions of the selected articles also had to relate to issues faced by student researchers working in the fields of advanced cancer, palliative care, or end-of-life care. Articles that did not fit these criteria were excluded. All four authors were involved in the review process and screened titles and abstracts.

Data Extraction

Articles that related to the research question and fit the inclusion criteria were selected for full-text review. The full-text articles were read, and information about journal scope, type of article (e.g., empirical or commentary), research approach (e.g., qualitative or quantitative), methods, and pertinent findings was extracted and entered into an Excel worksheet for review. The authors then met and selected the final seven articles to be included in the review (Table 1). Summaries of each article were written, and an outline of pertinent findings was created for presentation herein.

Table 1. Characteristics of selected articles

	Journal scope	Type of article	Method	Research population	Patient population studied
Johnson & Clarke (2003)	Qualitative research	Empirical	Thematic analysis	Students	Cancer/HIV-AIDS/death/dying
Lalor et al. (2006)	Nursing	Empirical	Grounded theory	Students, supervisors, and transcriptionists	Women whose children have fetal abnormalities
Newbury (2011)	Nursing	Commentary	N/A	Students	Family caregivers (palliative care)
Nordentoft & Kappel (2011)	Social work	Commentary	N/A	Students	Drug users and terminally ill cancer patients
Price & Nicholl (2013)	Pediatrics	Commentary	N/A	Students	Parents of children with life-limiting illnesses
Rager (2005a)	Qualitative research	Commentary	N/A	Students	Patients with breast cancer
Rager (2005b)	Education	Commentary	N/A	Students	Patients with breast cancer

RESULTS

The number of titles, abstracts, and full-text articles reviewed and excluded were tracked and are reported herein in the form of a flow diagram following PRISMA guidelines (Figure 1). From the databases searched, 3,161 articles were identified for review. One additional article was retrieved from the snowball search through the reference lists of selected full-text articles. Of the sources that were reviewed, either partially (title and abstract) or in full, seven articles were ultimately included in the scoping review.

The articles selected for analysis originated from four different countries: Denmark, Ireland, the United Kingdom, and the United States. They provide a multidisciplinary perspective, including the disciplines of education, medical sociology, and nursing. However, only two of the references retrieved as part of the scoping review were empirical studies involving the collection of primary empirical data on the topic of interest (Johnson & Clarke, 2003; Lalor et al., 2006). The remaining articles were commentaries and personal reflections published in a variety of clinical and research journals. The literature retrieved was therefore largely anecdotal in nature,

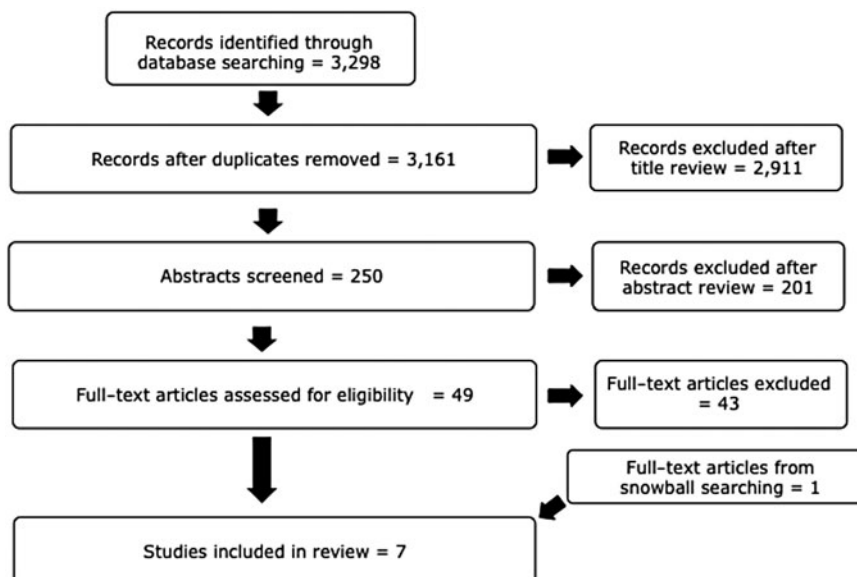


Fig. 1. Article selection process (based on: Moher et al., 2009).

relying on personal experiences instead of empirical studies with larger samples. Our research question about the psychosocial needs of students conducting research with advanced cancer and palliative care patients yielded very limited empirical research. We therefore retained commentaries and personal reflections as sources that could provide some insight into students' perspectives. An important result of this scoping review concerns the near absence of empirical research about students' psychosocial needs, while several commentaries suggest that students in this field have a high need for support.

The studies selected for analysis suggest that, while there are rewarding aspects to conducting research with palliative and advanced cancer patients and their families, the experience is generally perceived by student researchers as being a stressful one. The articles reviewed reveal that inexperience and a lack of training yield feelings of anxiety and unpreparedness for students when dealing with the kinds of methodological difficulties and ethical concerns that might be encountered during the research process (Johnson & Clarke, 2003; Price & Nicholl, 2013). Role conflict was found to be a struggle for student researchers as they attempted to differentiate between being a friend and data collector or to negotiate boundaries as a researcher versus a healthcare professional (Johnson & Clarke, 2003; Lalor et al., 2006; Newbury, 2011; Nordentoft & Kappel, 2011; Price & Nicholl, 2013). Student researchers were also burdened by concerns about how the research process might impact the participants while feeling a strong need to protect them and maintain confidentiality (Johnson & Clarke, 2003; Lalor et al., 2006). Moreover, the act of terminating the research relationship at the end of the study generated additional feelings of guilt and anxiety for student researchers (Lalor et al., 2006; Price & Nicholl, 2013).

Students conducting research in the fields of advanced cancer and palliative care reported feelings of extreme isolation and characterized this work as a lonely affair (Johnson & Clarke, 2003; Lalor et al., 2006; Newbury, 2011; Nordentoft & Kappel, 2011; Price & Nicholl, 2013). This was due in part to fieldwork often being conducted outside of the students' academic institutions and there being limited access to fellow researchers to discuss experiences, observations, and the decisions to be made (Johnson & Clarke, 2003; Nordentoft & Kappel, 2011). In addition, any team meetings that students were able to avail themselves of focused largely on issues related to the research process and did not offer an opportunity to reflect on students' experiences or to discuss their feelings or concerns (Johnson & Clarke, 2003).

In the context of conducting advanced cancer and palliative care research, students were often engaged

in intimate conversations that required significant therapeutic skills and empathy. One study found that, while listening to participants' stories, student researchers often developed their own health-related and existential fears (Johnson & Clarke, 2003). Many students reported that the emotional weight of conducting this type of research was as challenging as the intellectual demands of their research training. Specifically, many student researchers experienced compassion stress and psychosocial challenges that led to emotional distress and various psychosomatic responses (Johnson & Clarke, 2003; Rager, 2005a; 2005b; Lalor et al., 2006; Newbury, 2011; Nordentoft & Kappel, 2011; Price & Nicholl, 2013). Several aspects of conducting this type of research led students to feel extremely vulnerable, particularly the emotional nature of conversations, multiple role conflicts, heightened moral responsibility, and a lack of preparedness, as well as perceptions of isolation and insufficient support from mentors and peers (Rager, 2005a; Nordentoft & Kappel, 2011).

Summary of Research Findings

Despite the fact that there is minimal empirical literature with a dedicated focus on the psychosocial needs of student researchers in the fields of advanced cancer and palliative care, the retrieved commentaries and editorials helped to answer the research question. Three themes related to the psychosocial needs of student researchers were identified across the sources: (1) training and supervision, (2) emotional support structures, and (3) self-care strategies. These three themes represent the most discussed needs of student researchers in the English-language evidence base. The remainder of this section expands on these themes.

Training and Supervision

One of the main concerns for students conducting advanced cancer and palliative care research was the need for proper training and supervision. To be better prepared to conduct studies in this field, students needed explicit information on the emotional nature of this type of research (Rager, 2005a; 2005b). In addition, students needed better preparation and practical strategies to deal with the various challenges that are inherent to the research process (Johnson & Clarke, 2003; Rager, 2005a). Specifically, skills were required to negotiate access to this vulnerable population (Johnson & Clarke, 2003; Price & Nichol, 2013), obtain informed consent (Nordentoft & Kappel, 2011), conduct effective interviews (Johnson & Clarke, 2003; Price & Nichol, 2013), engage in roles while maintaining appropriate boundaries (Johnson & Clarke, 2003; Lalor et al., 2006; Price & Nichol,

2013), end the research relationship (Lalor et al., 2006; Price & Nicholl, 2013), and undertake data analysis in stages to alleviate the stress of immersion in such highly sensitive data (Price & Nicholl, 2013).

In addition to obtaining practical skills related to tasks in the research process, students needed training in relational competencies and interpersonal skills in order to effectively engage with participants and other team members in this highly emotional field of research (Nordentoft & Kappel, 2011; Price & Nicholl, 2013). Specifically, a nonjudgmental approach and attention to both verbal and nonverbal communication seem to be necessary (Price & Nicholl, 2013). Reflective competencies were also important to help student researchers process their experiences (Price & Nicholl, 2013). Furthermore, education about self-care strategies appeared crucial to offset the emotional challenges associated with this type of inquiry and to afford student researchers effective tools to cope with the heavy demands of this work (Rager, 2005a; 2005b; Price & Nicholl, 2013).

Alongside training for specific skill development, students reported a need for supportive supervision. It seemed important for supervisors to be aware of and to have insight into the possible methodological, ethical, or emotional issues that might arise when conducting research in this particular field. Students preferred open and approachable supervisors so that any issues could be raised and discussed without judgment or reproach. The effective supervisors were those equipped to provide counseling and support to deal with such issues (Johnson & Clarke, 2003).

Emotional Support Structures

Given the psychosocial challenges and emotional impact of conducting research on advanced cancer and palliative care, student researchers reported needing appropriate and accessible emotional support structures. There appeared to be a need for structures to be explicitly built into the research design, therefore ensuring that students had access to and received adequate support (Johnson & Clarke, 2003). Moreover, emotional support structures could include both peer and expert debriefing (Johnson & Clarke, 2003; Rager, 2005a; 2005b; Lalor et al. 2006; Nordentoft & Kappel, 2011; Price & Nicholl, 2013).

Emotional support structures also appeared important for students to feel adequately supported, to generate team building, and to assist student researchers in maintaining appropriate boundaries (Johnson & Clarke, 2003). Peer and expert debriefing can help students develop relational and reflective competencies (Nordentoft & Kappel, 2011) and work through any fears that arise as they engage in an area of highly sensitive work (Johnson & Clarke,

2003). Furthermore, intentional strategies that are put into place to provide appropriate emotional support can help student researchers manage the emotional impact of conducting research in advanced cancer and palliative care, thus making them less vulnerable (Johnson & Clarke, 2003; Rager, 2005a; Nordentoft & Kappel, 2011).

Self-Care Strategies

In order to maintain their physical and emotional well-being, student researchers reported needing deliberate and effective self-care strategies. Most frequently, authors expanded upon the need for emotional self-care strategies to offset the emotional impacts of conducting research in advanced cancer and palliative care (Rager, 2005a; 2005b; Lalor et al., 2006; Newbury, 2011; Price & Nicholl, 2013). Specific strategies included developing critical self-awareness and reflexivity competencies (Newbury, 2011); keeping a journal or diary to engage in reflexivity (Rager, 2005a; 2005b; Lalor et al., 2006; Newbury, 2011; Price & Nicholl, 2013); and participating in peer and/or expert counseling to debrief and process any difficult feelings or stress that the student researcher might be experiencing (Rager, 2005a; 2005b).

Strategies targeted at enhancing both physical and emotional well-being have been suggested elsewhere in the literature. Specifically, relaxation techniques and exercise have been proposed as potentially useful approaches to self-care for student researchers (Rager, 2005a). Additional self-care strategies have included maintaining a balance between home and work (Johnson & Clarke, 2003; Rager, 2005a; 2005b), fostering informal support networks (Rager, 2005a; 2005b), and engaging in hobbies and travel (Rager, 2005b).

DISCUSSION

Researchers in any field of inquiry may experience some of the methodological difficulties and concerns inherent to the research process. The consequences of conducting research for the researcher are possibly compounded when lines of inquiry focus on highly sensitive topics (Lee, 1993). While there is limited research on the needs of students in this specific field, some of the knowledge about the impact of conducting research on sensitive topics in general may be applicable to students doing research in palliative care and advanced cancer. For instance, a study of 30 public health researchers working on various sensitive topics (e.g., violence) called for better preparation to reduce the risks faced by researchers (Dickson-Swift et al., 2007; 2008). Research in advanced cancer and palliative care involves specific challenges. It could

also be argued that the negative impact of conducting this type of research is more of a concern for neophyte researchers who lack experience and have not yet learned to cope with such challenges. Moreover, some authors have discussed the challenges and emotional effects on such individual research team members as data collectors, transcribers (Gregory et al., 1997), and coders (Woodby et al., 2011; Ellington et al., 2013). These impacts can be multiplied for student researchers, who often fill all of these roles throughout the research process.

The current scoping review demonstrates that little is known about the psychosocial needs of students conducting research in advanced cancer and palliative care. However, what is clear is that there is a significant emotional impact on student researchers engaged in this type of work. Their psychosocial needs identified to date have largely been based on personal reflections and editorials. While this offers some important beginning insights, more empirical data are needed to better understand the experiences of students conducting research in this area. This includes improved understanding of any positive and negative impacts on student researchers, including the prevalence of these impacts, what factors influence students' experiences and how (e.g., the research process, the research environment, personal attributes, and the added demands of graduate school), and the short- and long-term implications of any emotional impacts on students' health, productivity, and sustainability in the field. With a better understanding of students' experiences, researchers can begin to more explicitly identify and understand students' psychosocial needs and how these might be addressed. Existing support structures can then be identified, and additional empirical interventions to support student researchers can be developed and tested. Furthermore, an understanding of students' needs can inform a set of guidelines designed to meet these needs and protect all those involved in conducting emotionally charged research (Rager, 2005a; 2005b).

Understanding and addressing the psychosocial needs of students conducting research in advanced cancer and palliative care are important for both individual student researchers and the broader field. Students who are given adequate support and whose needs are addressed appropriately may be better prepared to manage the challenges that arise during the research process, including the methodological and ethical challenges inherent to advanced cancer and palliative care studies. These students may also be better able to process the emotional impacts of such work and engage in effective self-care strategies to reduce compassion stress and burnout. This is essential for students' own health and well-being and plays

an important role more broadly in the development of knowledge and sustainability in the field.

The need for more research in palliative care is well documented (Higginson, 1999; Lorenz et al., 2008; Steinhäuser & Barroso, 2009). Moreover, the need to develop a body of knowledge comprised of rigorous scientific studies is paramount. Student researchers not only make a valuable contribution to the development of knowledge with their scholarly work as trainees, but they also represent the next generation of researchers who will continue to develop the empirical evidence base of the field. Inadequate training and support may result in the production of less rigorous research, and could also lead to negative impacts on students' health and well-being, including the potential for burnout or feeling dissatisfied with their chosen field of study. In turn, students may fail to complete valuable research projects or drop out of training programs. Sufficiently addressing the psychosocial needs of students training in advanced cancer and palliative care is crucial to fostering high-quality research and promoting retention of researchers in the field.

Adequately training and supporting student researchers and helping to maintain their emotional and physical well-being ultimately contributes to the sustainability of the field of advanced cancer and palliative care research. This, in turn, will promote the advancement of knowledge in the field and enhance capacity building, as student researchers become supervisors who are well equipped to effectively manage themselves and their research teams while mentoring the next generation of researchers.

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