

Qualitative Research on End-of-Life Care: Unrealized Potential

Abstract

Care for dying patients falls distressingly short of what people need and expect. According to patients, the most pressing issues in end-of-life care are adequate pain and symptom control, appropriate use of life sustaining treatments, and support of patients and families. These three foci are the ‘basic science’ of end-of-life care. The subjective experiences of patients and their families, and the organizations and culture that provide end-of-life care, are complex social phenomena that are best examined using the approaches and methods of qualitative research.

However, general medicine journals, the main vehicles for communication between researchers and health care providers, seem to undervalue the potential contributions of qualitative research. This underrepresentation is at least partly because reviewers used by general medicine journals often hold misconceptions about the purpose, methods and assumptions of qualitative research that almost always result in papers, even good ones, being rejected for publication.

In this paper a very brief overview will be provided of qualitative research methods, illustrations from our own research of misconceptions held by general medicine journal reviewers about qualitative research, and describe how empirical research using qualitative methods can contribute to improving end-of-life care.

Care for dying patients falls distressingly short of what people need and expect,¹⁻⁶ and improving the quality of care delivered at the end of life is one of the principal obligations of 21st century medicine. As research agendas are forged to improve care for the dying,⁷ we are confronted with two important questions: What do we need to know? How do we acquire this knowledge?

According to patients, the most pressing issues in end-of-life care are adequate pain and symptom control, appropriate use of life sustaining treatments, and support of patients and families.⁸⁻¹⁰ When formulating research that will help understand and improve the quality of end-of-life care, these three areas of investigation, which have the experiences of patients at their core, are obvious foci with which to begin. The patient’s experience of pain and other symptoms, decision-making regarding life-sustaining treatments, and the experiences of patients and families are the ‘basic science’ of end-of-life care. Additional research priorities include the organization and culture of end-of-life care delivery. These foci, the subjective experiences of patients and their families, and the organizations and culture that provide end-of-life care, are complex

social phenomena. What is the best way to explore and understand organizations, cultures and experiences?

It has long been recognized in the social sciences, such as sociology and anthropology, that these issues are best examined using the approaches and methods of qualitative research. This is increasingly being appreciated by investigators in health care¹¹⁻¹³ and health services¹⁴ research. However, despite these advances, general medicine journals, the main vehicles for communication between researchers and health care providers, seem to undervalue the potential contributions of qualitative research. General medicine journals, some of which allow considerable space for end-of-life issues, predominantly contain research reports from scientists who employ the methods of quantitative research (for instance, epidemiology and clinical trials). In other words, there is silence where there should be a rich discussion of the issues (that is, the 'basic science') crucial to improving the quality of care provided for the dying.

The purpose of this paper is to examine the potential usefulness of qualitative research on end-of-life care and demonstrate that this potential has not been fulfilled. We hope this paper will sensitize researchers, editors and reviewers to the potential contributions of qualitative research to improving end-of-life care. In the spirit of constructive criticism, we will provide what might be termed 'audit and feedback' regarding qualitative research in end-of-life issues. The paper is organized into four sections. First, we will provide evidence that qualitative research is underrepresented in general medicine publications of empirical research in end-of-life care. Second, we will provide a very brief overview of qualitative research methods. Third, we will provide some illustrations from our own research of misconceptions held by general medicine journal reviewers about qualitative research that lead to these manuscripts being rejected. Fourth, we will describe how empirical research using qualitative methods can contribute to improving end-of-life care.

Qualitative research is underrepresented in publications of empirical research on end-of-life issues

Table 1 shows the results of a MEDLINE search of articles describing original empirical research in the area of end-of-life care by journal. The study involved an English-only keyword search using 'end-of-life', 'palliative care', and 'euthanasia', between January 1999 and July 2000. Excluded from this study were commentaries, research review articles, book reviews, and letters to the editor. The journals were selected to represent different journal types. In the study period, the six general medicine journals published 23 articles of empirical research on end-of-life care, of which only three used qualitative methods. These journals published many more articles on end-of-life issues, but these were mostly commentaries.

We also examined the two most influential science journals, a journal that specializes in end-of-life care, and a journal that specializes in social science research in health care. The two science journals published no empirical research on end-of-life care. The end-of-life specialty journal published ten empirical studies of end-of-life issues, none using qualitative methods. By contrast, the social science journal, which

Table 1. Empirical research in end-of-life articles by journal (January 1999 – July 2000).

Journal	No of articles: empirical research in end-of-life issues	No of articles: empirical research using qualitative methods in end-of-life issues
<i>General medicine journals</i>		
New England Journal of Medicine	2	0
Lancet	2	0
JAMA	10	1
Annals of Internal Medicine	1	0
British Medical Journal	6	1
Canadian Medical Association Journal	2	1
<i>Science journals</i>		
Science	0	0
Nature	0	0
<i>End-of-life journal</i>		
Journal of Palliative Care	10	0
<i>Social science journal</i>		
Social Science & Medicine	6	4

specializes in multi-method research, published six empirical studies on end-of-life, four using qualitative methods. These findings suggest that few empirical studies on end-of-life are published given the size of the problem and the overwhelming evidence that the quality of end-of-life care needs improvement.

Before we discuss why we think qualitative research in end-of-life issues is under-represented in general medicine journals, we will provide a brief overview of qualitative approaches and methods.

Overview of qualitative research methods

Qualitative research is an interdisciplinary, interpretive field of inquiry. It has existed for as long as people have asked questions about social phenomena. Modern qualitative research consists of analytic procedures that facilitate the interpretation of data collected using a variety of techniques including field observations, personal interviews, focus groups, case studies, document analysis and other sources that describe routine and problematic moments in organizations and individual lives. The goal of qualitative research is to understand the meaning of social phenomena in their natural settings, particularly for the people and organizations involved. Qualitative research methods may be used to develop basic descriptive knowledge, evaluate programs and develop theory. The resulting knowledge can be used to guide the interpretation of quantitative findings, develop research instruments (for instance, surveys), guide practice and research, and influence policy.

Qualitative research methods are often contrasted with quantitative research methods which seek to quantify, or count, phenomena under various conditions, and test defined

hypotheses about causality or relatedness, based on numerical data. Quantitative research strives for generalizability and controls intervening or confounding variables using sampling and statistical methods. Qualitative research seeks to understand the particular characteristics of the phenomena under study and admits the influence of all intervening variables as data to be described and analyzed. Qualitative researchers accept that research interventions, including researchers themselves, may influence the phenomenon under study, and try to be honest and transparent about personal biases that inevitably shape research interests, questions, data collection, analysis, interpretation, writing and the dissemination of results. In recent years, qualitative researchers holding a post-modern conceptual framework contend that both the investigator and research participant hold perspectives that are filtered by language, profession, gender, class, and ethnicity, that participants are often unable to fully explain what they think or feel, and that investigators can never fully understand the people and phenomena they study. Consequently, these researchers do not feel a need to impersonate the aloof, objective ‘other’, but can freely include emotion, multi-voiced text, and responsibility, often with political overtones, in their arsenal of interpretive and expressive tools.

A fundamental tenet of research is that the purpose of the research will influence the approach and shape the research question, and it should be the research question that determines the appropriate research method.¹⁵ This facilitates innovation because all questions are in play rather than forcing investigators to choose from a limit range of questions predetermined by their limited knowledge of only a few methods (for instance, clinical epidemiology, randomized controlled trials). For example, Table 2 shows four research questions about the same issue: two amenable to a quantitative study and two amenable to a qualitative study.

Table 2. Quantitative and qualitative research questions.

Quantitative research question	Qualitative research question
How many dialysis patients think completing an advance directive is a good idea?	Why do so many dialysis patients think that advance directives are good thing, but so few actually complete one?
How many dialysis patents have completed an advance directive?	What is the role of an advance directive in people’s advance care planning?

Table 3. Research questions, research strategies and data sources.

Research question	Research strategy	Data sources
What does it mean? Why is it meaningful?	Phenomenology ^{28,29}	Interviews, written anecdotes
What is it (system, institution) like?	Ethnography ^{30,31}	Interviews, observations
What are they (people, group) like?		
What is happening? How/why is it happening?	Grounded theory ^{32,33}	Interviews, observations, document analysis
How do they communicate? What are they communicating?	Discourse analysis ^{34,35}	Interviews, dialogues, document analysis

Qualitative research consists of a wide range of heterogeneous methods and approaches. Table 3 provides examples of four types of research questions and relevant qualitative methods. Since a characteristic of good research is the appropriateness of the method, investigators that can use both quantitative and qualitative research methods, sometimes in combination, will be able to explore many important questions that are not amenable to single-method investigators. Later in this paper we will describe a few of these different qualitative research methods and their contributions to end-of-life care.

In the next section we will discuss misconceptions held by general medicine journal reviewers that will relate to aspects of this overview of qualitative methods.

Qualitative research is often misunderstood by journal reviewers

Why are qualitative studies in end-of-life care underrepresented in general medicine journals? One reason may be that some qualitative studies and corresponding manuscripts are inferior in quality. We believe, however, that another reason is that reviewers used by general medicine journals are biased against qualitative studies because they often hold misconceptions about the purpose, methods and assumptions of qualitative research. This is not surprising given that most physicians, who serve as reviewers for these journals, are trained exclusively in quantitative research methods. These misconceptions on the part of general medicine journal reviewers almost always result in papers, even good ones, being rejected for publication. In this section, we have reproduced some actual comments from general medicine journal reviewers that illustrate these misconceptions. These reviews pertained to five papers reporting qualitative studies on end-of-life care that were rejected by at least one general medicine journal, three of which have been published in other general medicine or specialty journals, two are being reviewed elsewhere.

Each of the reviewers' statements included in this section was received in response to a submission of a manuscript to a general medicine journal, illustrates an important misconception about qualitative research, and formed part of the grounds for the paper being rejected by the journal. The reviews are organized by methodological category and accompanied by a brief rebuttal.

Sampling

- (1) *Two other problems have to do with failure to provide demographic data of the non-participants in order to determine the representativeness of the participant study sample.*

Sampling strategies in qualitative research generally reflect the fact that the phenomenon under investigation is not known or understood clearly in advance. Sampling strategies purposefully target individuals or circumstances that are thought to be most likely to illuminate these phenomena. Qualitative researchers do not attempt, or claim, to produce findings that are generalizable to populations. Their interest is in the experiences of the particular people involved. Review (1) implies that the participants of this study have nothing of interest to contribute to our understanding of end-of-life

issues. A basic assumption of qualitative methods is that the perceptions and experiences of each individual are important and should be, at least, recognized.

(2) *Also no correlations were attempted involving participant characteristics and outcome measures.*

Review (2) raises the question: how would a researcher know what characteristics to correlate? Without a conceptual framework, grounded in a more detailed knowledge of the phenomenon under study, statistical correlations based on the standard battery of demographics are often fishing expeditions. Moreover, the outcome of this study was a description of the perspectives and experiences of the participants. What 'outcome measures' should be singled out for correlation?

(3) *The study group was confined to patients with esophageal cancer. My guess is that a significant percentage of younger women with breast cancer would insist on more information and more control over treatment decisions. The authors should discuss this possibility.*

Perhaps patients with esophageal cancer would have perspectives that are different than patients with breast cancer, but the former were being studied. To describe the perspective of breast cancer patients, one would need to ask them in another study. The reviewers' comments suggest an unrealistic expectation about the generalizability of qualitative research findings.

(4) *The study group focused on a relatively uncommon devastating malignancy with a poor prognosis requiring major life-threatening surgery. The informed consent process might be quite different for cosmetic surgery, low risk function restoration surgery, et cetera. The authors should speculate in the discussion about the applicability of their findings to these other conditions.*

The purpose of the study in question was to describe the perspectives of a particular group of patients. To discuss the applicability of this description to patients with other conditions would indeed be speculation (that is, guesswork, not research).

(5) *Generalizability – this paper seems to describe in-depth interviews with 32 people. What can be meaningfully said based on the comments of 32 people? For most researchers 32 is a pilot study that is then pursued in a larger study.*

Whereas comments (3) and (4) posed questions about the generalizability of the findings across different research contexts, or under significantly different circumstances, comment (5) poses a more fundamental challenge about epistemology and evidence, namely whether it is even possible to gain knowledge about a phenomenon of interest based on a limited number of cases. Since the journals that rejected the manuscript each present case studies on individual patients as part of their regular content, this question is particularly salient. Although the epistemological foundations of qualitative research are beyond the scope of this chapter, where qualitative research elucidates aspects of phenomena that are recognizable and reconcilable with the experience of those involved, it is as valid a source of knowledge as any other.¹⁶ This reviewer would have been accurate in writing, 'For most quantitative researchers 32 is a pilot study.'

Analysis and interpretation of data

(6) *One observation is novel and perhaps important: 'Of the 10 participants who discussed advance care planning with others and received a negative response, none completed an AD form.' This simple observation on a small number of subjects is provocative and well worthy of a prospective trial.*

Because this reviewer is focused primarily on the generalizability of the findings, she has failed to recognize that the finding in question, which was not described in any previous literature, already provides reasonable grounds for physicians to attend to this particular aspect of advance care planning in practice. The key message here is that this particular feature of the phenomenon does happen, and may happen to readers' patients.

(7) *A lot of anecdotal data are presented, but it is hard to identify trends clearly. The researchers did not explore other significant variables that would affect planning, such as religion.*

Qualitative research findings are often labeled 'anecdotal'. However, qualitative data are collected and analyzed systematically, that is, the opposite of anecdotally. In addition, it is often difficult for qualitative researchers to distill extensive amounts of textual data and analysis into the very limited space and format provided in general medical journals. This is another systematic bias against qualitative research that, to be fair, is beyond the control of reviewers.

Writing and presentation

(8) *The six elements of the study explored would be better presented without the verbatim quotes.*

(9) *I am uncertain whether this paper is appropriate for [journal name]. If so deemed, I would recommend that it be rewritten as a letter to the editor (with all the quotations omitted and with sufficient space dedicated to the study's limitations).*

The verbatim quotes are data selected to perform two important functions. First, they reveal the genuine voice of the participants, which is a key strength of qualitative methods. Second, they provide evidence that the analytic interpretations were not merely fabricated, but reasonably reflect the data on which they were based.

General comments

(10) *The authors have tackled a very difficult area to study and are to be commended; however, I believe this article would have more impact if published in a journal that includes more quasi-experimental/qualitative research. Biases apparent in this article make it unsuitable, in my opinion, for publication in [journal name].*

This reviewer has perfectly underscored the focus of this section. She is not convinced that qualitative studies can produce knowledge that would be of interest to

physicians who are the principal readers of a general medicine journal, yet she has failed to offer appropriate and meaningful criticisms of the qualitative methods themselves. The reviewer's judgement is unrelated to the appropriateness of the method to the question, rigor of the actual investigation, or quality of the manuscript. We believe it is based on fundamental misconceptions about the purpose and methods of qualitative research.

Contributions of qualitative research on end-of-life issues

Qualitative research can contribute to our understanding of end-of-life issues and to improvement of care for the dying. As mentioned above, some of the fundamental issues in end-of-life care involve complex social phenomena that are best explored using qualitative research methods. Moreover, different qualitative methods or approaches can contribute different types of knowledge pertaining to end-of-life issues. At the University of Toronto Joint Center for Bioethics we have a strong emphasis on qualitative methods in end-of-life research. In this section we will use examples from our own work to illustrate four qualitative research methods and a specific contribution each has made to understanding and improving end-of-life care. There are, in addition, other fine examples of qualitative research on end-of-life issues in the research literature.

Content analysis

Content analysis is a quasi-qualitative method whereby text is coded and then reduced to a unit-by-variable matrix that may be quantified. It assumes that the meaning people assign to words or experiences are common sense, or taken for granted. The limitation to content analysis is that meaning is not always so transparent or simple. Singer, Martin and Kelner developed a taxonomy of quality end-of-life care using a modified content analysis of interviews with three groups of people: dialysis patients, people with HIV, and residents of a long-term care facility.⁸ This study was the first to describe quality end-of-life care from the perspective of patients. The taxonomy of end-of-life care from the patient's perspective highlights the needs of dying patients and so can shape the care that should be provided.

Ethnography

Ethnography 'combines research design, fieldwork, and various methods of inquiry to produce historically, politically, and personally situated accounts, descriptions, interpretations, and representations of human lives', and can help researchers to better understand the beliefs, motivations, and behaviors of participants or groups of participants.¹⁷ Ethnography is often used in cultural studies. Bowman used ethnography to develop a description of Chinese-Canadian seniors' perceptions of end-of-life issues.¹⁸ These perceptions had not previously been described in detail. Although there is tremendous diversity in any cultural or religious group, Bowman's findings

provide assistance to health care providers and policy makers to better understand the cultural perspectives of some Chinese patients.

Grounded theory

Grounded theory is ‘a general methodology for developing theory from data that are systematically gathered and analyzed’ and is appropriate for exploring phenomena that are conceptually dense and involve social processes.^{19,20} It is particularly useful for developing a theory or a conceptual framework in contexts where none exists, or where the existing frameworks appear flawed. Singer, Martin, and others, have used grounded theory to develop a new conceptual model of advance care planning from the perspectives of dialysis patients²¹ and people with HIV.²² Before this work, the prevailing conceptual framework for advance care planning was based on the perspectives of ‘experts’, and all advance care planning intervention studies based on the expert-derived framework had failed to achieve their desired outcomes. The new model of advance care planning is grounded in the experiences of patients and, therefore, is more suitable for framing research interventions and guiding education and practice.

Phenomenology

Phenomenology is a qualitative method based in phenomenological philosophy that helps to develop a description of ‘what it feels like to...’.^{23,24} Phenomenology as a research method helps investigators understand the experience and perspective of individuals, particularly within the context under study. Workman used phenomenology to describe the problems and conflicts related to ‘futile’ treatment in the Intensive Care Unit (ICU) from the perspective of twelve ICU nurses and physicians.²⁵ This study provided a forum for the voices of ICU providers who anguish over conflicts regarding treatment decisions. It provides policy and practice recommendations that seek to prevent and lessen the conflict that creates so much moral anguish among providers, patients and families.

There are also other qualitative methods that may make a useful contribution to the end-of-life literature but which, to our knowledge, have not yet done so. Two such methods are case study and participatory action research. A *case study* is ‘an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident’.²⁶ The focus of case study research is the system or institution that serves as the context for the phenomenon under study. *Participatory action research* is a method for the study of practice, language and organization with a commitment to action that reforms or improves.²⁷ It has its philosophical roots in theories associated with liberation theology and human rights activism which are oriented toward social, economic and political development to improve the lives of vulnerable people. It has also been used to improve a variety of systems and institutions such as classrooms and schools, community groups, corporations, and industries.

Conclusion

Qualitative research can make significant contributions to understanding and improving end-of-life care. At the center of end-of-life care are the experiences of patients and their families. Other core issues include the organization and culture of end-of-life care delivery. Qualitative research methods are well suited to provide insight into these fundamental issues, the 'basic science' of end-of-life care. Lamentably, qualitative research in end-of-life is underrepresented in general medicine journals, at least partly because of bias among its reviewers who hold misconceptions about the approaches and methods of qualitative research.

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