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Understanding Complexity in Care: Opportunities for Ethnographic Research in Palliative Care

Matthew P. Grant^{1,2,3,4}, Jennifer A. M. Philip^{1,2}, Luc Deliens³, and Paul A. Komesaroff⁴

Abstract

Background: Ethnography has been used to address a broad range of research questions in health care. With ethnographic research methods it is possible to gain access to the complex realities of health care practice as it occurs, through interpreting the nuances of individual and team behaviours, the roles and dynamics of care provision, and the social impacts and influences of illness. The provision of clinical palliative care is complex, involving multidisciplinary collaboration across different health systems, and is subject to a multitude of personal, cultural and environmental influences. This complexity demands creative methodological approaches to research in palliative care, of which ethnography plays an important, if infrequently utilised, role. **Aim:** This article aims to explore potential opportunities of ethnographic methods for palliative care research. **Findings:** Ethnographic methods focuses on behaviour in the 'natural' setting of participants, to create theoretical descriptions of events, cultures, interactions and experiences. In palliative care these methods may provide nuanced understandings of illness, relationships and teams, communication, medical education, complex care provision, and novel or changing health practices. Of particular importance is the potential of these methods to understand complex practices and processes, and engage with under-represented population groups who may be excluded from interview research. **Conclusion:** Ethnography offers important opportunities for future research in palliative care and should be considered as part of the 'research toolbox' to improve understanding of the complex nature of care provision and the experiences of illness and loss.

Keywords

ethnography, qualitative research, medical anthropology, palliative medicine

Introduction

In 1965, Glaser and Strauss published "Awareness of Dying", exploring the experiences of death in hospitals.¹ This work involved six years of ethnographic observation, witnessing how dying occurred in hospital, and the behaviours, provision of care, and communications related to death. At a time when terminal diagnoses were frequently concealed it illustrated the challenges of communication and aligning awareness between staff, patients and families, and through this described systemic issues of dominant knowledge frameworks and institutionalised roles.² This was revolutionary research, illuminating the tensions related to dying in the hospital, the differing patterns of 'awareness contexts', and provided a framework to improve provision of end of life care.^{3,4} In addition, this research led to the development of 'grounded theory'; a methodology which informs a significant share of current qualitative research.

Despite the major attention upon the work of Glaser and Strauss in the field of social sciences, ethnography has remains an underutilised method in palliative care research.^{4,5} Ethnographic methods have significant potential to progress understanding and inform future palliative care provision. These methods can shed light on the complex realities of the

clinical and social practice of palliative care, through interpreting the nuances of individuals' and teams' behaviours, the roles and dynamics of care provision, and the influences of culture, society and relationships on illness. Ethnographic methods can enable insights not accessible from other data collection methods, including structures, processes, and behaviours the interviewed participants may be unaware of themselves.⁶ Ethnography can access how life and care occurs in reality, rather than 'how it was perceived'.⁷ Of particular importance in palliative care is the potential of these methods to bring

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about understanding of complex practices and processes, and engage with population groups who may be unable to participate in interview research.

The provision of palliative care is complex, involving multi-disciplinary collaboration across different health systems and teams at the site of care provision; and is subject to a multitude of personal, cultural and environmental influences.⁸ It differs from many other medical specialities in its broad focus of illness as a physical, social, spiritual and psychological phenomenon, that affects all members of the care team, and the resultant care is the sum of many processes and relationships between formal and informal caregivers. Ethnography methods are ideally suited to apply in palliative care. To understand the impact of care requires an appreciation of the dynamics, influences and relationships, in addition to the outcomes.⁹ This demands creative methodological approaches to research, of which ethnographic methods play an important, if infrequently utilised, role.

This article aims to explore potential opportunities of ethnographic methods to be applied in palliative care research, to inform palliative care clinicians and researchers of how it might be applied for future work. It provides a commentary on the potential for ethnographic method in palliative care, formed through a scoping of the medical ethnographic literature in, and outside of, palliative care.¹⁰ Using the framework of LeCompte and Schensul, we will explore aspects of palliative care research where ethnography may provide important or new insights, with existing literature used to illustrate application of these methods.¹¹ In addition, an overview of ethnography methods and considerations is provided.

Ethnographic Methods: an introduction

Ethnography is a domain of research arising from sociology, directed towards undertaking first-hand observation and participation in the natural setting of the participants.^{12,13} Its epistemological basis is constructionist; that knowledge is socially constructed and embedded.¹⁴ It is underpinned by the fundamental premises that (i) behaviours have meanings, (ii) actions make sense in context, and (iii) actors are knowledgeable in their own culture and actions.^{11,14} This places particular emphasis on the research context, in particular accessing the 'natural setting' of the participants, and thus observing behaviours in the social environment that they occur.

The research methods applied in ethnography are heterogeneous, focusing on the collection of data from the natural setting of the participations through observation and/or participation in their environment.¹⁴ Historically ethnography has been characterised by complete immersion in the research environment over long time periods; yet modern applications have placed greater emphasis on accessing the natural setting through a variety of means, often for shorter duration with defined research foci.¹⁵ Fieldnotes, based on the observations, interactions and reflections of the researcher are the major form of data collection. These data are frequently supplemented with interviews, document review, and potential media such as

video or the creation of artwork, which can be utilised for data source or methodological triangulation.¹⁶ While primarily a qualitative methodology, quantitative data may be collected (such as numbers of participants engaging in a specific behaviour) to support results. Data analysis may be informed by differing analytical frameworks, with commonly used methods including thick description, grounded theory and forms of thematic analysis.¹⁷

Ethnography methods may sit alongside other qualitative and quantitative methods to explore research questions. In contrast to interview research the researcher is able to witness health care being enacted, rather than participant's reflections and perceptions. This may result in differing and complementary viewpoints, each focusing on different aspects of a phenomenon to construct a deeper understanding. For example, a study of district nurses providing palliative care demonstrated they engaged in many differing care tasks, roles and behaviours when observed.^{18,19} Through interviews the participants were unable to describe many of these tasks or did not associate them with formal care, but detailed important perceptions on how they fulfilled their roles and the significance of this.

Ethnographic methods can be applied to a range of research questions. Notable examples of its use in health care settings include Erving Goffman's study of institutionalising behaviours of patients in psychiatric facilities, *Asylums*; Becker's *Boys in White*, exploring medical student culture as they transition to becoming doctors; and the work of Glasser and Strauss.^{20,21} LeCompte and Schensul suggest these methods may be of significant utility for research focused on.^{11,22}

- defining complex problems and their boundaries, effects, and stakeholders;
- accessing systemic, cultural and environmental influences on behaviours;
- exploring complex processes that involve many participants and systems, with the potential to understand measures of outcome, and unanticipated effects; and
- answering questions and accessing populations that cannot be addressed with other methods.

Opportunities for Ethnographic Research in Palliative Care

Ethnography has been utilised in a range of health care settings, focusing on numerous aspects of care provision and participant experience. Reflecting upon recent empirical studies and LeCompte and Schensul's framework for potential applications of ethnography, we will explore aspects of palliative care research that may benefit from the use of ethnographic methods.

A central premise of medical sociology is that the practice of medicine reflects and reinforces dominant cultural and social processes.²³ The context and nature of palliative medicine continues to evolve in relation to the societies and personal influences. For instance, the general practitioner who is not talking to his patient with advanced cancer about potential support by palliative care, may be influenced by the structural elements

of the palliative care provision in the country, by his training at medical school, by his own attitudes towards palliative care, but also the attitudes of the patients towards palliative care and the overall death literacy and societal culture regarding death and dying. Technological advances (eg telemedicine, social media), changes in legislation and medical practice (cannabinoids, palliative sedation) and social processes (death cafes, perceptions of palliative care) represent alterations to the structures of care provision. Ethnography enables exploration of these influences and their impact upon individuals, relationships, teams and care provision; to make sense of this 'messy world' in which palliative care is provided. Anne-Mei The's ethnographic studies on the withholding artificial hydration and euthanasia depicted the narratives of the patients, health professionals and families as they were confronted by these challenging situations, describing the nuances of decisions to withdraw care and the dying process.^{24,25} Through interviews and observation, The's work described how these challenging practices were perceived by participants, and how they were approached and enacted in practice.

A common challenge to palliative care research is understanding the complexity of issues relevant to end of life care, particularly those that are difficult to enunciate or emotional.²⁶ How an issue is discussed as a concept may differ considerably from how the same interviewees or respondents relate to, and enact behaviour relating to that same issue. This was a key premise of Awareness of Dying; that health professionals engaged in behaviours to anticipate dying, yet failed to recognise or communicate the dying process.³ Ethnography offers the opportunity to witness how these issues are enacted and discussed in real life. For example, spirituality is a concept that has historically been difficult to define, that many individuals may relate to and interpret in diverse ways.²⁷ In a study of spiritual end of life care in nursing homes, Gijbets et al. demonstrated that staff were involved in many activities and interactions that engaged spiritual dimension of care, despite being unable to identify many of these acts formally.²⁸

Ethnography in medicine has frequently focused on care practices occurring within the clinical encounter. These methods allow for the full context of the clinical interactions to be explored, including non-verbal behaviours, the impact of the physical space, recording of clinical data, care provision activities, and team collaboration.^{2,29} Collier et al.'s recent video-reflexive ethnography study used the novel medium of video to detail the relationship of palliative care patients to the home environment.³⁰ It highlighted important safety and quality issues, the expertise of patients in care provision, and the reshaping of care practices in the home setting.^{30,31} This method observed participants and then engaged them in self-reflection, providing complementary accounts.² As a research method, it engages participants to reflect on, and refine their own practices.³² These methods may be highly relevant in palliative care practice when applied to health professional communication and complex care processes.

Palliative care provision involves technical and procedural skills, while engaging forms of emotional and moral work

that place significant responsibility on individuals, which in turn influences collaborative efforts.² An Australian study examining end of life care in an Intensive Care Unit (ICU) described the processes and tensions involved in care provision when staff believed care to be futile.³³ The authors highlighted the lack of control many staff perceived in the ICU context and identified communication and coping strategies employed to influence clinical decision making 'upstream', engage in self-management practices, and improve patient care. Ethnographic methods are ideally suited towards understanding these influences and relational dynamics that form the bases of care provision, especially given the multidisciplinary nature of palliative care.

A challenge of qualitative interview research is the need for participants to communicate verbally, leading to the exclusion of populations who may be unable to vocalise, or whose voices may be difficult to interpret. This is particularly relevant in palliative medicine, where conditions such as stroke, dementia, head and neck tumours, and neurodegenerative diseases are common. Observation allows access to these important populations who are under-represented in research. While it is acknowledged that there must be important ethical safeguards in place when including those with cognitive impairment in research, there is also an obligation to include such frequently neglected and vulnerable individuals.³⁴ Ethnographic observation provides a considered approach to elucidate their behaviours and experiences which has been used in dementia research.^{28,35} A recent article by Chapman et al. poignantly portrays the profound meanings communicated through behaviours and objects by a man with dementia who was no longer able to verbalise, and whose deliberate actions observed by the researcher conveyed both intention and meaning.³⁶ There are many populations that are poorly represented in research and ethnography may enable a greater understanding of their experiences.

A novel application for ethnography has developed in interventional research.^{37,38} This is recognition of the complexity of many interventions: involving multi-component care provisions and numerous providers, health systems, and care processes. Outcome measures frequently only assess results of these processes and do not take into account the dynamics of care, interactions between these processes or unanticipated outcomes.⁹ The Medical Research Council's recent guidance on complex intervention evaluation focused on three components; the evaluation of what is delivered through the intervention, how the impact delivers change, and the context of the intervention and how it affects implementation and outcomes.³⁹ A study by Finch et al. used ethnography to construct a complex behavioural and educational intervention in HIV pre-exposure prophylaxis.⁴⁰ It identified particular social and structural factors that affected medication adherence and acceptability, to inform the design of an intervention that addressed the behaviours related to medication use at multiple points. A Danish study embedded a researcher within the clinical environment through a complex intervention for first episode psychosis to explore the impacts and processes of a clinical trial.⁹ This

study examined the intervention processes, impacts, and outcomes. An interesting focus of this research explored the outcomes of the intervention for the patients, who derived value from the systematic approach to support and education through a period of significant personal instability.⁹ Additionally, it may explore how staff engage with research processes, identifying which processes which may be limiting (such as gatekeeping) and those which can be improved. Ethnographic methods are uniquely placed to examine many aspects of inventions, to explore first-hand how staff, patients and their families engage with these care processes, and identify unintended outcomes as they occur.³⁷

Methodological Considerations

Ethnographic methods are heterogenous, and their empirical application may differ significantly in accordance with research focus, methods of data collection and practical considerations. Historically, ethnography is time consuming through data collection and analysis. Yet for many research questions extensive periods of observation may not be required, and could be addressed through shorter and well-defined periods of observation focused on matters pertinent to the research aims.³⁷

In Palliative Care, there are important considerations relating to study design, with requirements varying widely between environments and populations. Ethics committees may have minimal experience in appraising these methods, in particular in palliative settings, thus engaging proactively with well-articulated research plans may prove fruitful.⁷ The consent process may alter behaviours and relationships with participants, as it is widely described that participants behave differently when aware they are being observed, known as the Hawthorne effect.³⁷ When consent is appropriate, developing strong relationships with participants over time may diminish these effects.³⁷ Developing relationships with patients and staff is central to ethnographic fieldwork, yet may alter the dynamics of the relationship beyond researchers and participants, and influence “which stories are told and whose voices are heard or muted”.⁴¹

The palliative care research environment and data may pose further considerations. Hospital spaces are traditionally occupied by individuals in formal roles (staff, patient, visitor), each with differing activities and levels of access.²³ Embedding oneself in a staff role may allow observation of many health care practices, but also limit the availability to collect data due to competing tasks and influence how other participants act around the researcher. The role taken within the research environment and any pre-existing professional roles or experiences can influence data collection and analysis, thus self-reflection on how these may influence the collection and interpretation of data is important.³⁷ Negotiating these roles, as being both insider and outsider, staff and researcher, participant and observer, and the tensions and juxtapositions that develop from these differing perspectives is crucial to the understanding the environment and phenomena of interest.²³ It should be considered how the researcher is embedded within existing

social and therapeutic relationships, in particular staff perceptions of their role and impact on patients and their care, which may lead to ‘gatekeeping’ to research sites and participants.⁷ Data analysis is frequently complex and informed by sociology and philosophy literature, and the authors would encourage engaging interdisciplinary research teams with relevant expertise to advise and supervise analyses.

There are limitations to ethnographic methods regarding generalisability of results.³⁷ Most ethnographic research is confined to a single or a small number of research sites, and are reflective of these communities. However, the results aim to construct theories, understand processes and outcomes that may have broader applicability. Other study methodologies may be used to evaluate the extent or applicability of these changes in larger or different populations. In interventional research, these methods may be of considerable utility for pilot design and to identify how and which processes of the intervention to evaluate.³⁷

Implications for Future Research

Ethnographic methods offer important opportunities for palliative care studies and should be considered as part of the ‘research toolbox’ to improve understanding of the complex processes of care provision and the experiences of illness and loss. While ethnography have been seemingly underutilised, it is hoped that through novel applications of its methods and increasing multidisciplinary collaboration in research that ethnography may serve a far greater role in the future of palliative care research. This ethnographic approach may address blind spots in current research, enable access to under-represented populations, allow exploration of clinical interactions and communication, and changing health practices and care provision as they unfold. Palliative care is embedded within local, national and international health, cultural and social systems, and ethnography may facilitate an understanding of the complex relationships that contribute to the provision of palliative care and identify factors and behaviours that may be amenable to future service development. In the fifty years since ‘Awareness of Dying’ was published, societal and clinical factors have shifted immeasurably, and it is anticipated that the results of ethnographic research will continue to have a significant role informing the future of palliative care.³

Authors Contributions

All authors (MG, JP, LD, PK) contributed to the development and writing of this manuscript.

Declaration of Conflicting Interests

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Ethical Approval

Not applicable, because this article does not contain any studies with human or animal subjects.

Informed Consent

Not applicable, because this article does not contain any studies with human or animal subjects.

Trial Registration

Not applicable, because this article does not contain any clinical trials.

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