

Using observation as a data collection method to help understand patient and professional roles and actions in palliative care settings

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Abstract

Background: Observational research methods are important for understanding people's actions, roles and behaviour. However, these techniques are underused generally in healthcare research, including research in the palliative care field.

Aim: The aim in this paper is to place qualitative observational data collection methods in their methodological context and provide an overview of issues to consider when using observation as a method of data collection. This paper discusses practical considerations when conducting palliative care research using observation.

Findings: Observational data collection methods span research paradigms, and qualitative approaches contribute by their focus on 'natural' settings which allow the explanation of social processes and phenomena. In particular, they can facilitate understanding of what people do and how these can alter in response to situations and over time, especially where people find their own practice difficult to articulate. Observational studies can be challenging to carry out: we focus on the potentially problematic areas of sampling, consent and ethics, data collection and recording, data management and analysis.

Conclusion: Qualitative observational data collection methods can contribute to theoretical and conceptual development and the explanation of social processes in palliative care. In particular this contribution to understanding care structures and processes should improve understanding of patients' experiences of their care journey and thus impact on care outcomes.

Keywords

Consent, ethics, observation, palliative, qualitative research, research design

Observation as a qualitative data collection technique is widely used in many research fields, particularly anthropology where the ethnographic observational tradition is strong.¹ In palliative care research it is less common – for example, a review of qualitative research in palliative care showed it to be used in only a fifth of studies.² In our own field of primary palliative care, our recent review of the district nurse's role in palliative care provision revealed that observation is rarely used as a data collection method, even where the questions posed might indicate its suitability.³

Observational research techniques have advantages over other qualitative data collection methods when the focus of research is on understanding actions, roles and behaviour. Interviews are commonly used to facilitate discussion about

healthcare and the experience of health or illness, but they are limited when the aims of the research include understanding structures and processes that underpin health or healthcare. Put simply, an interview allows someone to say what they do; an observation allows you to see directly what someone does.

In this paper we draw on our experiences in past^{4–6} and current studies using observational methods, from others' research, and from experiences shared during a workshop we facilitated on the use of observational methods (www.pcco-ngo.org.uk/speakers/Innovative_research_methods.pdf). We begin by setting the method of observation in its methodological context, then address the main focus of the paper – the possibilities and practical considerations of employing observation as a method for data collection.

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Observation: Methodology and method

Observational data collection methods span research paradigms, from structured observations that count instances of events, to highly unstructured participant observation. It is argued that ‘questions of method should be secondary to questions of paradigm, which can be defined as the belief system or world view that guides the investigation, not only in choices of method but in ontologically and epistemologically fundamental ways’.⁷ Paradigms that tend to favour qualitative methods frequently describe actions in context, and draw from philosophical traditions that believe in the social and cultural meanings of actions and how they are shaped by the interpretation and construction of stimuli and situations.¹ Observation as a methodology clearly contributes to these understandings, as it can be employed in ‘natural’ settings, rather than those set up for research purposes such as interviews.¹ The contribution of observation to such paradigms can lie in explaining social processes and phenomena, often through developing typologies. Much observational research has drawn from the ethnographic research tradition. Classic examples in palliative care that have done much to move knowledge forwards in this field include the typology of dying ‘awareness contexts’ developed through observational data, and which clearly shows the methodological contribution of observation to the development of theory,⁸ and work examining emotional labour in the hospice setting.⁹

Our aim in this paper is primarily to explore the practical considerations of the use of observation as a method rather than a methodology. Texts are suggested here for readers who wish to explore the methodological context of observation further, including exploring the history and role of ethnographic research in palliative care.^{1,7,10–16}

When might you use observational methods?

Observational methods are useful for understanding what people do – their roles, actions and behaviour – and how these can alter in response to situations and over time. We have used observation to explore aspects of healthcare that practitioners find difficult to articulate. For example, we found that, when interviewed, district nurses struggled to describe their role in providing early support visits to palliative care patients.¹⁷ When observed, however, skills and actions that had not been described were revealed,⁴ which had not been shown by other interview-based studies.^{3,17}

Other examples of recent observation studies in palliative care (see Table 1) include exploring care of the dying in home, hospital and hospice settings,¹⁸ examining administration and understanding of chemotherapy from patient and physician perspectives,^{19,20} and examination of symptom discussions in oncology outpatient consultations.²¹ These studies focus on structures and processes, examining behaviours such as

talk and action in consultations, provision of nursing care, and the role of family carers. Whilst interviews can be used to ascertain the interpretation of ‘actors’ in the field, observation can be critical to elucidating people’s behaviour and provides information not obtained by other methods.

Observation, conducted with due care and attention can be particularly useful in working with those who might be excluded from studies due to perceived research burden (i.e. those who are dying), communication issues (i.e. hearing impairment, dementia), issues of age or maturity (the very young and the very old), and where issues of social desirability may affect responses (i.e. drug use, sex workers).¹ However, observation is not just a technique for difficult situations, but is useful in uncovering the taken-for-granted work of health professionals.

What roles can be taken by the observer?

An important consideration is where to place oneself on the continuum of observer to participant, and why. The complete participant’s true identity and purpose are not known to those observed, whilst the complete observer role removes the researcher from social interaction.¹⁴ Researchers are rarely at either end of this continuum, and their role often changes as the research progresses.¹⁵ Issues to consider include the observer’s own professional role, the possibilities for influencing behaviour and changing the dynamic of the situation, and the practicalities of how to observe and record observations. Researchers also need to consider what they bring to the encounter as insiders or outsiders.¹²

Strengths and weaknesses of different observational roles need to be considered in terms of being part of someone’s world, maintaining role, bias, and privacy and consent. Traditionally, anthropologists immersed themselves in the world of ‘outsiders’, often for prolonged periods.²² This participant role reflects a belief that ‘deep familiarity’ is required to obtain the best data, achieved by getting emotionally, physically and socially close to the people being studied.²³ It is difficult to fully participate in some worlds, for example those of lone or elite workers,¹⁵ and perhaps because of this, healthcare researchers frequently examine the familiar, as insiders.

Both positions have different advantages and are dynamic. For example, an outsider may move towards an insider perspective as participation in the setting develops. This increasing familiarity with a setting can affect how the observer ‘sees’ and interprets what is happening. Proponents of insider observation argue that they have a privileged understanding of the situation, are less likely to misinterpret behaviours, can uncover valuable meanings, and easily gain trust and cooperation.²⁴ However, physical, mental and analytical fatigue may also be a consequence of prolonged insider participation.

Participatory roles may create difficulties with maintaining the role of researcher. There is effort required in maintaining

Table 1. Examples of studies using observation in palliative care.

Author, date, country	Purpose of research	Research findings	Overall research methods	Type of observation employed	Contribution of observations to the findings
Mills et al. ¹⁸ 1994 UK	To study the process of care of dying patients in general hospitals	Dying patients had inadequate symptom control, nursing care, and general medical attention.	Observation (between dying patients and nurses, of ward rounds, between doctors and nurses). Documentary analysis (nursing and medical records).	Non-participant observation	Dissonance between reported care and observed care implies that other methods (i.e. interviews) would not have revealed the poor care patients received.
Dean and Gregory ³⁰ 2004 Canada	To examine the phenomena of humour and laughter in the context of palliative care	Humour and laughter were widespread and important. They helped with building relationships, contending with circumstances and expressing sensibility.	Clinical ethnography (participant observation, interviews with patients, families and staff) in a 30-bed inpatient palliative care unit.	Participant observation	Observation of humour and laughter in action were powerful: allowed observation of physical and emotional manifestations of consequences of humour.
Bell ¹⁹ 2009 Canada	To explore cancer patients' perceptions of chemotherapy	Suffering is fundamental to people's preconceptions, understandings and experiences of chemotherapy.	Ethnographic approach incorporating observation and interviews.	Participant observation	Observation of natural conversations between patients revealed common issues that might not have been revealed in individual interviews or focus groups.
Rogers and Todd ²¹ 2000 UK	To investigate the process of communication between cancer patients and oncologists in outpatient clinics	Pain talk is a substantial topic, with doctor-initiated questions the prominent discourse feature. Limited information exchange and truncated talk.	Observation (and audio taping) of consultations.	Non-participant observation	Findings not possible without observation and offer new insights into how pain is managed.
Audrey et al. ²⁰ 2008 UK	To examine how much oncologists tell patients about the survival benefit of palliative chemotherapy	Discussion of survival benefit often vague or non-existent.	Observation of oncology consultations, interviews with patients pre- and post-consultation. Interviews with oncologists.	Non-participant observation	Felt that findings stronger as emerged from consultations as they occurred rather than retrospective interviews.
Griffiths et al. ⁴ 2010 UK	To explore how district nurses conduct early support visits with palliative care patients	Psychological needs described as being met informally through 'chatting', but observation revealed avoidance behaviour by district nurses.	Observation of district nurse visits with patients, interviews with patients and carers, focus groups with district nurses.	Non-participant observation	Contrasting data found from observations and interviews. Avoidance behaviour not described, only observed.

the ‘pretence’ of a participatory role,¹⁴ whilst also ensuring the researcher role is adequately addressed.²⁵ Subjectivity and bias are also potential weaknesses. Some argue that the position of complete observer is free from most of the potential bias that can arise from too close an affiliation with research subjects.²⁴ Increasing participation in a situation can increase the risks of subjectivity and bias, along with the drawback of being familiar with much of what is seen. However, subjectivity, or the use of self, is integral to the process of fieldwork and the construction of ethnographic accounts.²⁵ It is critical that an appropriate balance is found between an appropriate use of self, and subjectivity, using a reflexive approach to make processes visible. Roles are also increasingly constrained by the requirements of research ethics committees or other governance requirements, where the needs of informed consent procedures take precedence over a desired participatory role.

Practical considerations in observation

Planning an observational study

Careful preparation can maximize the opportunities offered by observation. Research gatekeepers (i.e. funders, research ethics and governance committees, participants) might infrequently encounter proposals using observational methods, and therefore have particular concerns. Observation may be perceived as more intrusive and threatening to participants than other forms of data collection. As a result, research ‘gatekeeping’ may be exacerbated in observational studies. Establishing personal legitimacy and credibility with gatekeepers and potential participants is likely to involve discussions about academic credentials, clinical background and the ‘personal front’ of demeanour and attire. Clinicians in particular may be perceived as ‘insiders’, knowledgeable and competent in clinical practice and contexts, which may either facilitate access or trigger concerns in those observed about judgement of their expertise.

See Box 1 for specific practical suggestions regarding this and other planning issues.

Sampling issues

Crucial sampling decisions include which sites, events, and persons are to be observed over what time period and how ‘bounded’ observations are likely to be. For example, in our own studies we had to decide whether to observe a district nurse during particular patient visits or throughout a shift. These decisions alter issues of consent, especially where the boundaries of the observation and its setting are less clear, and where unanticipated participants, such as patients’ relatives, may be present. Addressing these consent issues in an ethical fashion is likely to be critical to the success of the study, and is discussed now in more detail.

Box 1. Practical considerations before data collection commences from our own experiences and those shared at the observation workshop.

Funding and research ethics/governance applications

- Pre-empt questions about observation as a method by giving a clear, referenced rationale for the benefits of observation in your study and consideration of the ethical issues raised.
- Explicitly discuss issues of gatekeeping, access and consent, with reference to prior consultation with planned observation sites.

Access to research sites

- Meet gatekeepers and others in advance and in person so they can determine your suitability to observe in their clinical setting.
- Ensure gatekeepers and others are well briefed, so they can explain your study to others and champion your research.

Consent

- Information and consent forms need to be well designed with user input with regard to their language and format. The use of a photograph(s) of the research team can be helpful.

Consent issues

Consent issues can be complex in observation studies, and frequently central to the strict ethical and governance contexts within which research is conducted. Practical and ethical decisions need to be made about whether and how to obtain written or verbal consent from participants. This can vary depending on how bounded the setting is, whether participants are central or peripheral to the objectives of the observation and whether their participation is anticipated. Written consent prior to the observation from all participants might be considered to be the ‘gold standard’ and setting up a study in a way which facilitates this is likely to aid research approvals. Such advance written consent is more likely in a bounded setting (for example a clinic, or home) where only anticipated people are likely to be present. However many ‘classic’ observational studies in palliative care settings^{9,11,26,27} occurred in less bounded settings, such as wards or hospices, with participants whose presence could not be anticipated in advance, some of whom were peripheral to the objectives of the observation. Obtaining permission to conduct such studies now might be challenging, but appears possible, with recent examples of permission granted when the focus of the observation is the professional rather than the patient,^{28,29} and in less bounded settings.³⁰ Weigl et al.²⁹ discuss their obligations to preserve patient confidentiality and follow ethical principles, even where advance permission to observe patients, such as in the emergency room, had not been given. However, there are also accounts where obtaining ethics committee approval to conduct observation has been more challenging. An example is working with psychiatric patients, where concerns were expressed about their vulnerability and potential inability to give full informed consent. Ongoing discussions with the research ethics committee did facilitate a

way forward with the research. There are key points about the difficulties of requiring individual informed consent when using a participatory method that is essentially collective,³¹ and about observation enabling participation of those who may have been excluded from other forms of data collection such as interviews.²⁶

There are also temporal issues to consider. Obtaining consent well in advance of the observation may give the opportunity to discuss the study in more detail. In other circumstances consent may be obtained at the start of the observation episode for pragmatic reasons, or to minimize the time burden on observer and observed. The intent should be to avoid changing the nature of the observation itself. Ongoing consent has to be considered when multiple observations are planned, or during lengthy periods of observation. People must be able to leave, request that the observer leave, or withdraw from the study.

Conducting an observational study

Although a theoretical choice of a more participative role may be made, participation may not always be practical (for example with lone or elite workers)¹⁵ or valued. On the other hand observational roles may also move towards participation as the researcher becomes trusted and accepted.³² Many believe that an observer will always be considered part of the world they study, always having an effect on the phenomena being studied, whether or not they are drawn into participation. Examples from our own non-participant research include being invited to contribute to a clinical discussion about care and to participate in providing nursing care. It is important to consider how to respond to such situations, and how the response may affect the observational data. See Box 2 for further practical considerations.

There is a balance to be struck between sitting or standing out of the line of sight of participants to reduce influencing the 'normal' situation, and being able to observe. Where observers sit or stand will impact on what is seen and from whose perspective – for example, observing more body language from one participant than another. This may be unavoidable, but needs to be considered in analysis. Equally, sitting very obviously 'out of sight' may make the observer more conspicuous, may raise suspicion and could make observation itself difficult. Examining a setting in advance may be preferable, but not possible, especially when observation incorporates moving with a practitioner through a number of settings, or in private settings such as the home.

Consideration needs to be given to when data collection starts and finishes. This may be affected by formal consent (i.e. observation only possible when this is obtained from all participants), timing (i.e. whether to observe for a set period of time or a 'unit of care' such as a particular intervention), and fatigue (observer fatigue vs. blending into the setting).

Methods of recording observational data vary, and are driven by the research question and purpose of the observation. Common methods include audio-recording of speech data

Box 2. Practical considerations after data collection commences from our own experiences and those shared at the observation workshop.

Observational role

- Consider what might be best or appropriate for the setting under study and the observer skill set. For example some settings allow participatory tasks which facilitate observation such as bed-making and serving refreshments. In other settings such tasks would be obtrusive or may interfere unduly with the observed setting.
- Consider insider/outsider perspectives. If unfamiliar with a setting, acknowledge that you won't capture everything in a first observation. If familiar with a setting consider techniques such as just observing action and not speech for some observations.

Settings

- Consider a number of informal, non-data-collecting, visits to the observation sites before formal data collection begins.

Recording observational data

- Consider how much movement there will be in the observed situation when making decisions about the use of audio or video recording. This may affect the use of recorder and microphone type (size, visibility, portability). Consider how to manage recording failures.
- Audio transcriptions and observational field notes can be integrated if a note is taken of the recording time on a digital recorder when writing field notes.
- Field notes can be made contemporaneously, but it is possible to make them after the observational period, particularly when observing for shorter periods of time.

Observing poor or inappropriate care

- Consider in advance how to report care, disclosure procedures, and to whom (research supervisors, clinical managers, etc.). Reports should be objective, descriptive, and with possible explanations.
- Those observed also need to know that they can, and to whom, report issues regarding the observer.
- Consider the emotional effects on the researcher (and transcribers, etc.) of observational work and ensure support mechanisms are provided.

during the observation, making unstructured field notes (recording, for example, movement, body language, and initial interpretation of actions), and using a structured observation pro-forma (for example, a check box when a particular action is observed). Video recording is also possible, but requires a more structured observational format, such as an outpatient appointment, and can feel more intrusive. Audio recording can be unobtrusive, and can mean that observational effort can be concentrated on non-speech data.

A concern for many observational researchers, which featured strongly in the observation workshop, is the potential for observing poor or inappropriate care. There is an obvious duty of care to intervene if abuse is witnessed or care which could

be immediately dangerous. A more complex situation is the observer's role where care might be considered sub-standard but not immediately dangerous. Researchers have reported intervening to meet a patient's clinical needs,¹⁸ but more complex situations demand consideration about what might be regarded as 'reasonable' care by both those observed and the observer. Observers with and without clinical backgrounds are likely to differ in whether and how they identify poor care. It must be remembered that the observer also has a duty of care – to do no harm, to ensure privacy and avoid distress.

After observational data have been collected

Data management is an important issue in observational research, when there may be audio or video recordings to be integrated with observation notes, activity data and personal reflections. These can rapidly proliferate over hours of observation. Decisions are required about whether to keep data separate or integrated, and whether to use a CAQDAS software tool or similar to organize the data.

Member-checking, presenting data to participants to check for accuracy, can be difficult with field notes which may already have a layer of interpretation. Analytical decisions also need to be made if observational data are to be integrated with other data such as interviews – for example, whether they are to be coded together or separately. Reporting data can also be difficult, where anonymity is difficult to preserve in situations with small sample sizes, recognizable settings and the use of lengthy excerpts and descriptions. It is difficult to do observational data justice in a research report or article, and alternative methods of dissemination and report may be required.

Conclusions

Qualitative observational data collection methods have great potential to contribute to evidence and understanding in the field of palliative care. Observational methods contribute to theoretical and conceptual development in the field, and help to explain social processes and phenomena in a way which can contribute to clinical practice. For example, an understanding of how people enact roles and behave in particular situations is important if care quality is to be improved. Understanding, and subsequently changing, care processes in response to such understanding should improve patients' experiences of their care journey and hopefully improve outcomes. Observational research methods can make a significant contribution to understanding care structures and processes. Practitioners can find that data from direct observation are powerful and meaningful to them in a way that indirect data such as opinions voiced in an interview may not be. Observation appears to be an infrequent method of data collection at the moment, possibly because it can be challenging and time-consuming. However, we believe that the benefits to patients of such an approach make overcoming these challenges worthwhile.

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Conflict of Interest

None declared.

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