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Considerations and recommendations for conducting qualitative research interviews with palliative and end-of-life care patients in the home setting: a consensus paper

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ABSTRACT

Objectives To present and discuss the views of researchers at an academic palliative care research centre on research encounters with terminally ill patients in the home setting and to generate a list of recommendations for qualitative researchers working in palliative and end-of-life care.

Methods Eight researchers took part in a consensus meeting to discuss their experiences of undertaking qualitative interviews. The researchers were of varying backgrounds and all reported having experience in interviewing terminally ill patients, and all but one had experience of interviewing patients in their home environment.

Results The main areas discussed by researchers included: whether participation in end-of-life research unintentionally becomes a therapeutic experience or an ethical concern; power relationships between terminally ill patients and researchers; researcher reflexivity and reciprocity; researchers' training needs. Qualitative methods can complement the home environment; however, it can raise ethical and practical challenges, which can be more acute in the case of research undertaken with palliative and patients at the end-of-life.

Conclusions The ethical and practical challenges researchers face in this context has the potential to place both participant and researcher at risk for their physical and psychological well-being. We present a set of recommendations for researchers to consider prior to embarking on qualitative research in this

context and advocate researchers in this field carefully consider the issues presented on a study-by-study basis.

INTRODUCTION

The challenges of conducting qualitative research with sensitive and terminally ill groups have been well documented in the literature.^{1–5} As the scope and volume of palliative and end-of-life research grows, the use of qualitative methodologies across all care settings^{6–8} presents specific challenges to both participants and researchers. The use of qualitative methodologies, and in particular, unstructured or in-depth interviews, has several potential benefits not only to the exploration of the experiences of patients, their relatives and healthcare professionals but also to the planning, conduct and implementation of randomised controlled trials and in other study designs.⁷ While there is discussion in the literature on the use of qualitative methods in healthcare both generally and specifically relating to terminally ill groups such as patients at the end-of-life, little attention has been given to the challenges presented by collecting data in the home setting.^{9–10} The purpose of this paper is to present the views of researchers at an academic palliative care research centre who took part in a group consensus meeting to discuss their experiences of interviewing terminally ill patients in the home setting, and

to generate a list of recommendations for qualitative researchers working in palliative and end-of-life care.

Background

When setting up research studies in healthcare, we are asked to consider the ethical concerns for our target study population, in particular the terminally ill nature of the population, the sensitive issues and potential concerns which our research may lead to, and how we plan to address any distress we may inadvertently cause. Torjeson¹¹ defines the vulnerable adult as:

Someone aged over 18 who may need services because they are unable to take care of themselves or protect themselves against harm or exploitation. They may have a mental or physical disability, an illness or be elderly.¹¹

Palliative care patients may be considered to be a particularly vulnerable group with arguably limited opportunity to experience the benefit of today's research in the future.^{1 7} Interviewing terminally ill patients often requires discussing *sensitive* topics which, 'intrudes into the private sphere or delves into some deeply personal experience'.¹² This requires specific attention to issues such as sensitive and open questioning, researcher self-disclosure, the correct timing of interviews, a comfortable interviewing environment¹³ and the integral role of significant others in the interviews, such as partners and family members.

Across our portfolio of studies, we often state that we will conduct the interview in a location of the participant's choice, including their home. This is partly to minimise the inconvenience to the participant and, in the case of palliative care and end-of-life research, perhaps also due to necessity given their ill health and stage in life; the majority of our participants request the interviews to be conducted at their homes. However, the home can be very different to other settings;¹⁴ it is not just the location but an integral part of the interview itself.¹⁰ This can present particular challenges for researchers capturing qualitative data in palliative and end-of-life.¹⁵ To the best of our knowledge little attention has been given in the literature to the home as a venue for collecting data and its part in the research process.^{9 10 14}

Consensus meeting

Owing to the dearth of literature in this specific area, we first sought to establish a consensus of experience from an extensive, experiential knowledge base. Eight researchers (the authors) took part in the consensus meeting, of varying backgrounds including nursing (n=3), occupational therapy (n=1), social science (n=2), psychology (n=1) and palliative medicine (n=1). All have experience in qualitative research methodologies and interviewing terminally ill patients,

and all but one had experience of interviewing patients in their home environment. One further palliative medicine clinical research physician who was unavailable at the group meeting has also commented on the findings, adding their own experiences.

The researchers' experiences were based on their previous research experience in study and employment, and more than 300 interviews undertaken at the research centre across multiple projects. The vast majority of these interviews were with terminally ill patients in their own homes and offer unique insights based on combined professional experience, unavailable elsewhere.

The group discussion lasted around 1 h and a half, and was jointly facilitated by HP and AN. The topics initially selected for discussion were informed by the available literature and the personal experiences of the facilitators, and were expanded by other group members as the discussion progressed. Participants were encouraged in particular to reflect on the practical challenges or issues which they faced when interviewing terminally ill patients in the home, and any strategies which they had deployed to overcome these.

The discussion was recorded and fully transcribed. Key experiences, perspectives and practical strategies, including points of consensus and agreement, were identified and a list of recommendations for conducting qualitative research in this context was drawn up.

DISCUSSION

The salient issues which came to light during the consensus group meeting are discussed in relation to the similar issues set out in the literature; power relationships between terminally ill patients and researchers; whether participation in end-of-life research unintentionally becomes a therapeutic experience or an ethical concern; researcher reflexivity and reciprocity; researchers' training needs. Key consensus points and practical strategies identified in the group discussion are provided at the end of each theme. Following this, we present a list of practical recommendations and considerations for qualitative researchers working in this challenging field.

Power relationships and rapport building

The researchers consider rapport building with their participants to be a crucial component to any research interview.¹⁶ Often this needs to be performed quickly during a singular encounter;¹⁷ careful consideration needs to be given to the implications of this.¹⁵ Rapport building cannot be considered in isolation without reference to the balance of power between researchers and participants. Although qualitative research may look to minimise power imbalances,¹⁸ power relations may still exist during different stages of qualitative research, with the researcher possibly perceived as the owner of expert knowledge and especially in a population that may have unmet needs and

the uncertainty of facing a terminal diagnosis.¹⁹ The information that participants share may be further influenced by a power imbalance due to a variety of factors including gender, socioeconomic status, ethnicity and professional background and importantly, interview location.²⁰

The very nature of qualitative research methods not only permits a patient-led dialogue, but in patients' social spaces, can complement the home environment allowing for a more holistic discussion.^{9 10} This in itself can facilitate the process of rapport building with the patient able to demonstrate their status as a social being. It can also be easier to identify with the patient as a person in their home environment, surrounded by their personal effects, than in a clinical setting where they are more defined by their clinical situation.^{10 18} This can help the researcher feel more of a connection with the patient,¹⁸ something our researchers felt to be important not only for facilitating good quality data collection, but also in consideration of the time these patients are investing in the research. The researchers felt that the home setting may also help to balance the power between patients and researchers; patients assume a host/hostess role and may feel less restricted, able to be 'more themselves' and more in control of the situation. However, the host/hostess role may lead to patients undertaking certain tasks in preparation for their guest (eg, housework), placing undue pressure of physical activity with implications for their well-being and the quality of the data collected.

The importance of these issues becomes all the more salient when including palliative and end-of-life patients in research and can be of particular concern to the researcher, particularly those who have a clinical background.¹⁸ Patients may use the research study as a way to access information and clinical advice. This may be an artefact of the way in which they were accessed and approached to participate in the first place, for example, receiving an invitation letter on hospital headed paper from a researcher with the title 'Dr' (clinical or otherwise); appropriate framing of the encounter is essential as direct access to the relevant clinical team is not possible.²¹ The researchers felt that to give such information and advice was not only beyond the remit of their research role, but also unethical.

Consensus points and strategies

- ▶ The home environment can facilitate more comfortable and 'giving' relationships between researcher and participant.
- ▶ Strategies used to build rapport and support 'good' interviews included preamble and chat relating to the home and family environment. This could take place prior to the interview and as a useful distraction technique during the interview if needed, for example, asking about photos at times of upset.

Those with no clinical background should be clear about their position from the outset to avoid

confusion and potential misinterpretation of information.^{18 21} Similarly, those with clinical backgrounds should also make it clear that their role is as a researcher but with recourse to the patient's clinical team, if needed.

Participating in research: a therapeutic experience or cause for ethical concern?

There has been some debate in the literature as to whether including palliative and end-of-life care patients in research is ethical, with the question raised as to whether it should even be carried out at all.^{22–24} Over recent years, however, this stance has become less common, with evidence supporting increasing opportunities for palliative and end-of-life patients to participate in research which it is hoped will lead to evidence-based clinical care.^{1 3 25} However, it can be difficult to assess the risks and benefits of taking part in research; indeed participants' own preferences about the risks and benefits may change with time, as their circumstances change and their illness progresses.²⁶ While it is not the purpose of this paper to revisit this debate, it does highlight some specific issues around undertaking qualitative interviews in the homes of palliative and end-of-life care patients which ought to be taken into consideration. These include consent to take part, perceived therapeutic benefits, the opportunity to tell their story and unplanned contributions from a loved one.

Informed consent

The researchers felt that, although important, the process of obtaining valid, informed consent at the time of interview can be burdensome, particularly for this patient population. Often, more than one consent form needs to be completed—a copy for the patient, research team and also their clinical team. This can take time and, for particularly frail participants at home, may contribute to fatigue, which can impact on the quality and time spent interviewing. This process may also interfere with the rapport building between patient and researcher as it takes attention away from the relaxed, social sphere towards the formal 'business' sphere and the need to adhere to regulatory requirements.¹⁶

Finding ways to minimise the burden of the consent process without diminishing the importance of the process is important both for the participant and the researcher, for example, taking consent in advance. However, caution is needed if considering this latter approach as consent may not remain valid if/when a patient deteriorates and approaches the end-of-life.²⁷ Owing to the potentially changing nature of the conditions faced by palliative and end-of-life patients, decisions to participate and capacity to make those decisions may change from one day to the next.¹

Consensus points and strategies

- ▶ Although time consuming it is important to go through the consent process immediately prior to *any* interview to check the patient is still able to participate in the interview.¹⁷
- ▶ To help minimise the ‘burden’ of the consent process researchers could consider making copies of single consent forms and posting these to the participant after the interview.

Storytelling

One argument put forward in the debate as to whether patients approaching the end-of-life should take part in research at all is that doing so means time taken away from sorting out affairs or spending precious time with loved ones.²⁶ Conversely, taking part in qualitative research, particularly interviews can unintentionally become a therapeutic process for participants. Patients have the opportunity to talk about issues with someone who is present and possibly presumed to be experienced in palliative care for the primary purposes of listening to what they have to say;^{28–32} patients may not feel they can open up to loved ones through a desire to protect them, nor feel health professionals have the time to listen.³³ The researchers reported that patients will often tell the researcher the story of their illness, bearing witness, regardless of the explicit aim of the interview; story-telling can facilitate the bonding process and participants may say something pertinent a structured interview guide had not accounted for.¹⁸ The home setting can also be a catalyst to this discussion; patients are likely to feel more relaxed in their home environment with more control over the timing and content of the interaction than they may have in a clinical setting.^{9 10}

However, the relative ease by which patients are able to open up and share their story with the researcher may in itself lead to emotional upset; the researchers talked about opening the ‘floodgates’ something which can be upsetting for both patients and researchers. Not all of the researchers have clinical backgrounds and for them, seeing participants (including companions) visibly upset through talking to them for the purposes of their research can be distressing¹⁸ and they can find it difficult to know how to act. However, participants’ distress may be appropriate and natural given their situation, forming part of the therapeutic process. Indeed, a patient may even cry because they are saying something powerful, even if that something is positive.

Consensus points and strategies

- ▶ Participant story telling can be an extremely positive but also emotionally challenging feature of interviewing the seriously ill, in particular in the home setting.
- ▶ Researchers should not presume that the patient does not wish to continue with the interview in the case of distress, nor take the paternalistic stance to make that decision on the patient’s behalf. Participants should

instead be asked whether they feel able to continue with conversation.

Unexpected guests

Another potential difficulty which often arises when interviewing patients in their home is the presence of relatives and/or caregivers, which from hereon in we will refer to as ‘companions’. This is a common experience among the researchers, perhaps unsurprisingly given the nature of the patient population. Interviewing couples together can have its distinct advantages but it also presents challenges^{34 35} which can be particularly pertinent in this context. Not only can it prove difficult to ‘separate’ the patient from their companion, but may also be unnatural to do so as couples in particular may converse ‘as a pair’.³⁵ As such, contingencies need to be in place.³⁵ It was agreed however that the resulting data may be different when interviewing a patient with a companion present, something which at the very least ought to be acknowledged.³⁵ For example, the researchers reported that often it is the companion who dominates the conversation which can make it difficult for the researcher to direct the interview as planned. Consensus points and strategies:

- ▶ It is considered appropriate for companions to participate in interviews (subject to the preferences of the participant), but researchers should ensure that informed consent to use their data is taken from the companion. In our studies this usually involves separate consent forms and participant information sheets.
- ▶ Strategies adopted to deal with ‘dominant’ companions included turning slightly to face the patient more than their companion or explaining politely that it is best to let the patient answer the question in their own words.

Researcher reflexivity and reciprocity

Vulnerability and impact of the interview in the home setting is not simply a concern for the patient being interviewed; researchers too can be vulnerable and this needs to be taken into consideration prior to embarking on data collection.¹⁸ Researcher reflexivity is on-going and is the extent to which the researcher discloses themselves to the patient and how they present themselves, extending to the environment in which the interview takes place.^{21 36} An interview is an exchange and although participants can and do share intimate information, the researcher can often give something back in return.^{10 18 31} This may be accidental, a way of building rapport with the participant¹⁵ or even a way of minimising the power imbalance so participants feel more comfortable in disclosing.²⁸ Indeed, participants themselves may expect something in return for taking part in the research such as information and/or someone to talk to,^{28 31} particularly from their ‘guests’.¹⁰

Views differ in the literature as to how neutral a stance researchers should take, particularly within

qualitative methodologies.³⁷ Some of the researchers reported difficulties in maintaining neutrality, particularly those with some clinical expertise;¹⁸ one of our researchers admitted to giving advice to a patient during the research process although this was more to help the patient to access services rather than provide medical advice per se. The bonding process, particularly in singular encounters such as research

interviews, can be an intense experience for both the researcher and participant.¹⁸ To persist with a stance of neutrality may for some be deceptive and potentially undermine the rapport and relationship which has been built; some of our researchers felt that it is best to be transparent about this and provide that advice if able and qualified to do so.²¹ This though, may lead to further complications beyond the research encounter and care needs to be taken not to lead participants to say more than perhaps they would have wished.³⁸ Two researchers had also experienced the dilemma of a patient attempting further contact at their difficult times.

Table 1 Recommendations and considerations for qualitative researchers undertaking interviews with palliative and end-of-life patients in the home

| | |
|------------------------------------|---|
| Consent | <ul style="list-style-type: none"> ▶ Carefully consider the mechanics of the consent process and be careful not to apply a 'one size fits all' approach across your portfolio of studies ▶ Ensure a process is in place to obtain informed consent from any companions who may unexpectedly join in the interviews, with a clear idea on how this situation will be handled should it occur. Clearly set out the consent process for companions in the study protocol and have all processes and documentation ready, with the appropriate approvals in place |
| Boundaries and researcher position | <ul style="list-style-type: none"> ▶ Ensure researchers are clear from the start of the study as to what their position is, how they present themselves and the boundaries they will put in place should participants request information and support ▶ Carefully consider and reflect on the extent to which bonds are made between them and their participants with a contingency plan in place in advance of data collection to deal with any instances of participants making inappropriate contact outside of the research study ▶ Accept, and be reflexive on, the fact that a truly neutral/emotion free stance may neither be achievable nor appropriate. Ensure adequate support is available for both researcher and participants throughout the duration of the study |
| Researcher training and safety | <ul style="list-style-type: none"> ▶ Ensure researchers are adequately trained to undertake the qualitative interviews in the first place, on how to deal with difficult situations and on any safety concern relevant to the study. ▶ Ensure a debriefing process is in place for researchers and, particularly for less experienced researchers, a senior member of the team reviews initial interviews to provide guidance and training |

Another significant issue which arises during reflexivity is that of researcher emotions. Researcher emotion should not be dismissed¹⁸ and can help to understand the life of the research participant.¹⁵ Some of our researchers admitted to being upset following interviews and most noted that they have profound memories of their discussions with patients when reading the transcript to their interview at a later date. This can be especially poignant and upsetting for researchers (and transcribers) when they know a patient has or may die soon. Some researchers need time to reflect following interviews; debriefing and having a mentor or simply being part of a research team is important in this area of research to researchers.^{18 39} This can also contribute to shared learning among teams, and for clinical researchers in particular, help to enhance understanding of clinical workforce roles, supporting engagement with clinicians in overcoming perceived barriers.

Consensus points and strategies

- ▶ Maintaining a neutral stance with this group of participants is challenging and can be counter-productive.
- ▶ Creating boundaries around the research process need not necessarily exclude a clinical encounter. One strategy used for dealing with clinical queries from participants is to 'post-pone' discussion of these issues until the end of the interview; participants would then be directed to contact the appropriate healthcare professional/service provider. In some more serious cases, research nurses were contacted to provide support for the patients (including those which attempted 'personal' contact with the researcher).
- ▶ To conduct an interview on 'auto pilot' and with control over your emotions may not lead to a good interview; to recognise the poignancy of the situation in which our participants find themselves is in itself a strength and to ignore this does not do justice to either them or the data collected. Opportunities for researcher debrief and peer support is considered vital.

Researchers' training and safety needs

It is important that researchers undertaking this type of research are able to recognise their own limitations and possible biases and ensure they can acquire the skills and knowledge they need.⁴ The researchers

raised areas in which they felt it important for qualitative researchers in this context to have some experience of, which broadly speaking included clinical/patient exposure, interviewing skills and techniques and researcher safety.

It can be helpful to have previous experience as a health professional in terms of familiarity with medical equipment and terminology, physical function and appearance, for example patients' ability to communicate. However, being unfamiliar with these aspects may also have advantages where assumptions are not made, permitting space in which unanticipated issues can be raised and discussed.⁴⁰ Safety issues for researchers are also paramount.¹⁰ Researchers need to know what to do if they find themselves alone in a patient's home and feeling vulnerable, and it is imperative that colleagues are aware of the researcher's whereabouts during the interview process. One researcher also recounted how she was advised against home visits for safety reasons, by the study research nurse, who arranged for her to carry out these interviews in clinic instead.

Consensus points and strategies

- ▶ For those unfamiliar with working with palliative or seriously ill populations, the opportunity to visit hospital or hospice wards and meet patients to get a feel for the problems they experience is recommended.
- ▶ Our researchers are trained in and follow two standard operating procedures designed to protect their physical safety when undertaking this kind of lone working in the home setting. One of these procedures outlines a 'buddy' system, which is designed so that the researcher checks in and out of their interview with a designated colleague who has access to full contact details for the participant and researcher.
- ▶ The other contains details on the safety procedures/good practice when conducting a home visit. This includes, for example, contacting the research nurse/gatekeeper prior to arranging the interview to check that a home visit is appropriate, and ensuring unrestricted access to the exit (although the difficulties of achieving this in practice were also acknowledged).

Recommendations and considerations for interviewing in the home setting

Based on the discussion outlined above, we present a list of practical recommendations and considerations for qualitative researchers embarking on interviewing palliative and end-of-life patients in the home-setting (see [table 1](#)). While some of these may seem like obvious, common sense statements, we feel it is important to overtly present them as to overlook them has the potential to place both the participant and the researcher at risk, particularly in this context.

CONCLUSIONS

When conducting qualitative research interviews in the homes of participants several ethical and practical

challenges can and do occur regardless of the context of the research study. However, interviewing terminally ill individuals in their own homes, in this case palliative patients and those approaching the end-of-life, can magnify these issues with the potential to place both the participant and researcher at risk for both their physical and psychological well-being. Using qualitative methods can complement the home environment with the research interview becoming therapeutic for the participant. However, researchers need to be aware of power relationships between the participant and the researcher, not only as it can bias data but could also be detrimental to palliative and end-of-life participants. When researching terminally ill patients, researchers need to adapt to the needs of this participant group. In doing so, researchers should reflect on the dynamics of their interaction with the respondent. We advocate researchers in this field consider these issues carefully on a case by case basis, rather than adopt a one-size fits all approach across their portfolio of work.

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