

Relational ethics in palliative care research: including a person-centred approach

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Abstract: The traditional approach to research ethics is to ensure that all ethical issues are adhered to through the scrutiny of research proposals by research ethics committees, themselves sitting within national research governance frameworks. The current approach implies that all potential ethical issues can be considered and mitigated prior to the research. This article is a perspective piece whereby we consider how this approach, on its own, is not enough to ensure ethical practice. We draw attention to the limitations of current ethical procedures in the inherent detachment between the researcher and research participants. We argue that applying a person-centred approach to research ethics allows for contextual and situational factors and places the relationship between research participants and researcher as central.

Keywords: ethics, ethnographic studies, informed consent, palliative care research, person-centredness, process consent, situated ethics

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Introduction

Traditionally, to ensure that research is carried out ethically, formalised governance frameworks require researchers to submit an ethical application to a research ethics committee who then scrutinise the planned research procedures.¹ With this approach, it is expected that the researcher will gain consent from research participants as a one-off process prior to the research. This is based on a potential participant's understanding of the purpose of the research and what taking part means. The process focuses on ensuring that all relevant information is provided in appropriate written or pictorial form to potential research participants with roles and responsibilities clearly explained. This must then be fully understood by any potential participants before agreeing to take part (or not).

The main difficulty with the traditional approach to research ethics is that it does not take into account the sensitivity and complexity of research ethics that can exist in the palliative care research context. This includes when involving people with cognitive impairment and dementia and

people who are ill and close to death. Furthermore, it has limitations when the research process is genuinely participatory in design, such as in forms of ethnography, action-oriented and co-design research. The outcomes and processes of such research methods are not necessarily clear prior to the research beginning and may even be different to those anticipated.² Hence, it is impossible for participants to give fully informed consent in advance.

In this perspective article, we highlight one of the limitations of the traditional method of gaining informed consent and the need to supplement this approach with a person-centred approach. Specifically, the requirement for researchers to identify potential ethical issues in advance and outline plans to rectify or minimise them. This is usually undertaken with no involvement from potential research subjects or participants, stakeholders or sponsors. We argue that ethical research practice in social and human sciences is always both contextual and relational and needs to be underpinned by person-centred values and principles. This is especially the case in the complexity

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of many care settings; including palliative care and particularly with the range of methodologies employed within qualitative research. In order to address these issues, we propose that the four principles of person-centred research be applied in this research context, connectivity, attentiveness and dialogue, participation and empowerment, and critical reflexivity.³ We provide examples from two qualitative research studies to demonstrate how these principles are applied in practice to ensure practice-based ethics. Further to this, we propose process consent⁴ as a person-centred and relationship-based model to ethical research practice in the ‘messy world’⁵ of palliative care.

Person-centred approach to research

Person-centredness is best understood as a broad culture that incorporates person-centred care; therefore, it is more than care per se.⁶ Because it is primarily about a culture, person-centredness is applicable to everyone within the environment and requires a set of coherent underpinning principles. These are clearly demonstrated in the following definition:

Person-centredness is an approach to practice established through the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons (personhood), individual right to self-determination, mutual respect and understanding.⁷

In the research context, certain philosophical values underpin person-centred research.⁸ Jacobs and colleagues,³ drawing on the core values of person-centredness, set out four core principles for person-centred research:

- **Connectivity:** it is in a person’s relational being that meanings about knowledge originate.
- **Attentiveness and dialogue:** attentiveness requires participants to be contextually aware of oneself, others and their connectedness as human. Dialogue is based on the underpinning values of person-centredness of respecting what others say without judgement and the construction of shared meaning.
- **Participation and empowerment:** within the context of person-centredness, participation is enabling voice and choice and is essential to a person-centred research

process. Participants have choice as to what level they would like to take part in the research process. Empowerment is relational and multidimensional and aims to enhance ‘self-awareness’, ‘self-esteem’ and ‘capacity building’.

- **Critical reflexivity:** to create awareness towards power relationships and its impact on the co-construction of meaning.

The person-centred approach to ethical research, based on an ethic of care, is always relational and situational; whereby choices made are morally based, fully consider the context in which the research takes place and take account of the individual’s lived world throughout a study.^{9–11} Within real research practice, ethical issues will arise and tensions will emerge throughout the process, meaning that decisions need to be taken in how these are addressed. The four principles of person-centred research can guide decisions that are taken and choices that are made as the researcher and others consider what is morally right or wrong in the context of a caring relationship with those who are participating.

The following two examples from the authors’ (A.L. and E.H.) own research retrospectively demonstrate how the above principles were applied in practice to ensure person-centred research practice based on relational and caring approach between the researcher and the participants.

Interviewing in the palliative care context – Mr Smith

Mr Smith was a 59-year-old man with primary lung cancer with multiple secondaries. He had completed radiotherapy and chemotherapy and taken part in a study intervention. Prior to interviewing Mr Smith about the impact of taking part in the study I (AL) was aware that his disease had been progressing and he was weak. Therefore, I considered that he may not feel strong enough to talk to me. However when I called to check he said that he would be happy to help. When I went to his home to interview him I was met at the door by his sister-in-law who said they were expecting me. Mr Smith’s son bounded down the stairs to say hello, introduce himself and take me to meet his dad. Mr Smith’s wife also came out of the bedroom to meet me and say that her husband was very tired, breathless and in a lot of pain and that the GP was currently with him and was trying to organise some further input. I offered to leave them if it would be too much but Mrs Smith

said her husband would not hear of phoning me to cancel the meeting. He wanted to help.

Mr Smith was propped up in bed with multiple cushions and pillows, I reiterated that we need not carry out the interview if he was too tired or unwell or simply did not feel able. I said it would be no problem for me to leave or equally I could stay with him for a while if he would like me to. His response was insistent that he wanted to do what he still could to help others and if talking to me could do that in any way then that is what he wished. We discussed the intervention and Mr Smith talked of difficulties in managing some of the aspects of it but had done the best he could and told me about the benefits he had from taking part.

Mr Smith's wife came back in to the room to discuss the plans being made with the GP to alleviate her husband's pain and breathlessness. After this he became more distracted and just wanted to talk about his life so I switched off the recorder and sat with him a little longer to listen to his stories.

Taking part in the study seemed to have been important to Mr Smith even at the obvious late stage of his illness and he wanted to share this with me in the interview. It was something that he felt he could do in the midst of his illness. It was an important connection with his son who he was very close to and they had worked on it together which must have had benefits for both of them at a time when patients and family members can feel helpless. Any benefits of maintaining a degree of physical capacity that could allow Mr Smith to see and interact with his grandchildren who gave him some obvious joy was golden to him. As he concluded, 'I'm not going to be cured but I can do something'.

For Mr Smith taking part in the research study was something that seemed existentially important and potentially beneficial to him as he approached his death. The consideration that rather than research simply involving the potential for harm to vulnerable people, that personal benefits are possible beyond any therapeutic effects of an intervention has been highlighted in other research. For example, a study looking at the patient experience of taking part in a clinical trial described that, even in the absence of any improvement in physical symptoms, participant overall well-being was improved after taking part.¹² The authors discussed the personal value

patients took from adopting altruistic motives as well as the potential to benefit from the relationship that they build with researchers. This ties with what is known about well-being in those that are terminally ill where themes of self-awareness, the existence of positive and meaningful relationships with others and the capacity for continued meaning are described as central.¹³

Observing real practice as part of palliative care research

In an ethnographic study in a hospice with a focus on observing 'being with' as it happened in practice, the traditional research ethic practice was followed.¹⁴ The following is an extract from the researcher's reflection (E.H.) as she started data collection after having adhered to the traditional ethical practice around gaining informed consent.

When I started the data collection and my field work I became surprised how much unrestricted access I was given. My presence was never questioned and staff were incredibly positive and warm towards me. The staffs' actions implied a great deal of trust. They were kind, engaging, open with me at all times. I realised that through the meetings I had with the management team and the nursing staff when explaining the study and gaining their consent, a trust had been developed and I had gained access based on how they perceived me and the relationship I had with them. This made me become very sensitive to the context and the relationship I had with the nurses. I felt cared for by the staff I was observing I felt a reciprocal sense of responsibility. I cared about them and I felt I owed them something in return for their trust in me. Having this unrestricted accesses strengthened my own sense of responsibility and concern for the nurses I was observing. As I progressed into the data collection this became a further concern for me as I was surprised and a bit disappointed in what I was observing. I never saw a nurse engage with a patient on the level I was expecting and aiming to observe. They were very task focused and had organised their care around physical care and comfort. For them this was 'being with' rather than being with as an emotional engagement. It was obvious that nursing staff were all very well intentioned but sometimes I observed interactions whereby they blocked expression of emotions, missed cues, were at times patronising in the way they engaged with the patients. Never allowing an opportunities for existential and psychological engagement to occur.

As evident in this extract, once data collection had started, an ethical concern was exposed which had not been possible to anticipate. Accordingly, no plan was in place for how to manage the situation. The questions that arose for the researcher were 'did the nurses really understand the focus of the observation when they gave their consent? Did they understand what ethnographic research meant e.g. observing and recording everything what was seen and heard?' While in the beginning the purpose of the research had been clear, it now appeared that the study would reveal that, due to the day-to-day manner that nursing practice was carried out, 'being with' was an existential and psychological engagement that was actually missing from the care. In this particular situation, the researcher had a moral duty to try to understand the participants rather than judge them. Ethnographic research is a valuable methodology for health and social care through its capacity, through observation, to shed light on what really happens in practice and how practice is constructed. It places a microscope on the taken-for-granted rules guiding day-to-day practice that can otherwise go unnoticed.¹⁵ However, it is the researchers' moral duty to ensure that the interpretation of practice and the scientific rigour of the study is based on enhanced understanding of participants' values, intentions and motives.¹⁶ Observation of real practice unravels an understanding of human behaviour which becomes evident to the researcher. However, in day-to-day practice, participants' embedded and taken-for-granted behaviour may be perplexing or contradictory. Therefore, the researcher may make insights that go beyond what participants' understanding of their own behaviour is.¹⁶ Raising participants' awareness of the limitations of their current practice may be an important first step to change practice. This must always be guided, however, by the principle that the researcher has a moral duty to understand the participants, why they came to do what they do and to make sense of their actions through understanding the desire and purpose behind them.^{14,16} As such this process reflects person-centred research ethics guided by the principles of non-judgement and a morally focused person-centred relationship between the researcher and co-researchers or participants whereby shared meaning is created.

The above examples demonstrate the application of the four person-centred ethical principles in research. We will now provide a practical guide for gaining consent in a person-centred way when

including people with cognitive impairment and those who are ill and close to death.

Process consent to ensure person-centred approach to research

The traditional approach to research ethics has for decades led to a tendency to exclude people with cognitive impairment and those who are very ill and close to death from participating in health and social care research. The reason being that this group of people have been seen as too vulnerable to take part based on cultural values that such people will have impaired cognitive decision-making abilities. This is now increasingly being challenged as unhealthy gate keeping¹⁷ which may diminish the right that the person has to make their own choices and thus denies them a degree of personhood.¹⁸ Such a blanket approach risks removing the opportunity for people to have their voices heard, the potential to benefit from a therapeutic process or the experience of contributing in some capacity to their wider world should they wish to do so.⁴ Furthermore, as Thorogood and colleagues point out, blanket exclusion of people with cognitive impairment as a result of dementia may hinder improvements in dementia research, care and prevention. However, allowing for true representation of this group of people in research and for them to be given their right to make their own decisions about participating in research presents researchers with extra ethical challenges. This means that careful assessment of the capacity for decision making in the process of informed consent is central.¹⁹ Furthermore, it also raises the need for a form of consent that is not based solely on cognitive decision making but instead values choice and experiential forms of knowing.

Process consent is an idea that has been around in some types of qualitative research for several years. A specific model for a person-centred, and thus relationship-based, approach to ethical consent has been developed by Dewing.²⁰ This model allows people with cognitive impairment and dementia to take part in research and goes beyond proxy consent. Process consent highlights the ability for people to express choice and respond to experiential encounters and situations that remain long after cognitive decision making is reduced below the legal threshold for informed consent. The relationship between the researcher and the person with dementia throughout the research process can enhance choice or diminish it further.

Accordingly, the model makes it clear that working out issues of consent is an ongoing process that occurs throughout the research.²⁰ Like situated ethics, it recognises that ethical decisions and actions are context specific and centred on the interdependency within a caring relationship and acknowledges that capacity is situational. Process consent is an approach that can be used in palliative care not only for those with dementia but also for patients with end-stage cancer and other incurable illnesses that are close to death as demonstrated in the example above. To allow for safe inclusion of such patients, it is necessary to consider a process for gaining consent that is used each time the person takes part, rather than just once at one point in the research.^{20,21}

The ‘process method’ of gaining participant consent in research comprises five aspects; however, it needs to be noted that they do not necessarily constitute a linear method. While the method offers a pathway for researchers, the process very much relies on researcher expertise in being able to engage with persons who have dementia.

Within this method, Dewing sets out three key questions:²⁰

- How do I know this person is consenting?
- What type of appreciations does this person have in showing/sharing their consent?
- How would this person demonstrate reluctance and objections?

The five key components of process consent are as follows:

1. Background and preparation: permission to access the person to establish basic biographic knowledge of the person. To begin, it is vital to ask ‘How does the person usually present themselves when in a relative state of wellbeing?’
2. Establishing a basis for capacity and other abilities: use of existing assessment or expert opinion of capacity. In the presence of capacity perhaps adapted informed consent process can be used. If capacity does not exist, the researcher needs to establish to what degree the person can make choices for themselves. Here, there is significantly less emphasis on the person’s ability to retain information than to appreciate how the verbal, non-verbal and overall bodily responses of the person may indicate

acceptance or objection and potential consequences – that is to appreciate how it feels to the person in broad terms. Hence, consent is not informed consent as such.

3. Initial consent: opportunities to look for the implied meaning in what is being said rather than correct language – adapted written information, use pictures, objects or props that contextualise the discussion or exchange.
4. Ongoing consent: monitoring and revisiting the consent – between interactions and even within the same interaction.
5. Feedback and support – reflecting on the process with research team/staff. Provide support to participants.

Throughout these processes, it is made clear that the researcher must look for verbal and nonverbal responses and indicators that suggest whether the person is wanting to consider participating with the research or not. The researcher then constantly works at building up a picture that enables them to know when ‘yes’ means ‘yes’ and ‘no’ means ‘no’, and to search for opportunities to look for the implied meaning in what is being said or indicated through embodied communication rather than looking for intellectually correct language. We argue that this model of consent is transferable to the palliative care context where the ethical debate on whether persons near the end of life should be considered ‘too vulnerable’ to be involved in research is far from settled. In this context, Gysels and colleagues,²² on the basis of their research, recommend that consent should be a continuous process to ensure it is sensitive to distress or alteration in an individual’s capacity, especially when capacity is rapidly declining.

Melding two approaches to ensure ethical practices

In this article, we have brought to light that all potential ethical issues cannot always be dealt with and mitigated prior to the undertaking of palliative care research as expected within the traditional governance frameworks. Decisions and choices may have to be made during the research process. These should be based on care and the relationship between the researcher and research participants whereby the researcher takes a moral position and is constantly aware of what discomforts arise and of the ethical issues that emerge and need to be addressed in the process. This may be implicitly understood by experienced researchers, but it is

not made explicit through the process of gaining ethical approval in the traditional way. At the best of times, the underpinning values and beliefs of person-centred research practice are embedded in the research process and person-centred approach adhered to by the researcher, ensuring ethical research practice. However, it is timely that the process is made more explicit and within this lies the challenge of how this is managed within research governance. Ethics committees need to be more open to this approach and accept that when involving people who are seen as vulnerable in research or when peoples' behaviour and practices are being revealed, research relationships based on person-centredness and the use of process consent are essential. Researchers, and research supervisors, need to make it more explicit in research proposals how they intend to use person-centred approach to ensure ethical research practices throughout the life of the research. With this, the traditional approach to research governance will be challenged to move from valuing a detached process to becoming being person-centred and situated whereby all decisions made within the research process are based on person-centred relationships and practices.

Conclusion

In this article, we have demonstrated how person-centredness situated in practice is needed in addition to the traditional procedural ethical approach to ensure ethical practice in many palliative care research contexts. Rather than being a scrutinising process by an external research ethics committee prior to the study starting, we have revealed how ethical research practice also needs to be contextual and located in practice. The four principles of person-centred research presented in this article can be the starting point in developing a research culture in palliative care which has person-centredness at its core. Supplemented with a process consent model, this can make explicit research proposals on how the principles will guide ethical practice. This is a process that will expose the real challenges inherent in palliative care research and raise awareness of the importance of paying attention to ethical relationships throughout the whole research process not only prior to research.

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