



ORIGINAL PRACTICE DEVELOPMENT AND RESEARCH

Practice development using video-reflexive ethnography: promoting safe space(s) towards the end of life in hospital

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Abstract

Background: There is international consensus of the need for improved palliative and end-of-life care in hospital settings. What is less clear is how such improvements might be realised in practice. Research and practice improvement methodologies need to acknowledge the relational, spiritual, moral and ethical as well as physical dimensions of death and dying if improvements in care are to be achieved.

Aims and objectives: The aim of this article is to explore the potential of video-reflexive ethnography as a practice development methodology to improve care of people with a life-limiting illness in the hospital setting.

Methods: The study used video-reflexive ethnography and was underpinned by an indigenous research ethical framework.

Findings: Study findings highlight the potential of video-reflexive ethnography as a practice development methodology. The reach of video extended internally and externally beyond immediate practice research sites to make hospital dying tangible. The research acted as a disruptive innovation, foregrounding peoples' (patients and families) expertise as well as that of healthcare workers. For some patient and family participants, the research offered a visual legacy.

Conclusions: The theories underpinning video-reflexive ethnography and practice development are closely aligned; the former has potential as a practice development methodology to promote person-centred palliative and end-of-life care. The underpinning philosophical, ethical and values framework through which it is applied, along with the skills and aptitude of facilitation, are critical if its potential is to be realised.

Implications for practice development:

The delivery of person-centred end-of-life care may be facilitated by:

- Healthcare workers seeing themselves and those they care for differently
- Healthcare organisations seeing their employees as well as patients and families differently
- Researchers also being prepared to see themselves differently
- The use of video-reflexive ethnography as a potential practice development methodology to meet these objectives

Keywords: Palliative care, patient safety, person-centred care, video recording, qualitative studies, practice development

Introduction

A significant and growing number of people cared for in acute hospitals have palliative care needs (To et al., 2011; Gott et al., 2013; Clark et al., 2014a). There is broad agreement in policy documents and research literature, however, that the needs of people with life-limiting illness and their families are not being met (McNamara and Rosenwax, 2007; Australian Commission for Safety and Quality in Healthcare, 2013; Institute of Medicine, 2014; World Palliative Care Alliance, 2014; Parliamentary and Health Service Ombudsman, 2015). The now-seminal Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT, 1995) demonstrated significant shortfalls in care at the end of life in hospitals. Healthcare workers frequently find it difficult to recognise and acknowledge that people are dying (Bloomer et al., 2013). They often find communication with patients and families difficult (Sasahara et al., 2003) and people's dignity comes under particular threat in the hospital setting (Pringle et al., 2015). Furthermore, there is a tendency for the focus to remain on 'cure', with investigations and active treatments continuing even until the last days of life (Hillman and Chen, 2009). The management of pain and other symptoms are frequently inadequate (McNamara and Rosenwax, 2007; Clark et al., 2014b). Moreover, the communication needs of patients and families remain to a large extent unmet (Hillman and Chen, 2009).

Despite extensive evidence identifying the needs of people with a life-limiting illness and their families (Virdun et al., 2015), what is referred to by Kaufman (2005) as the 'problem of hospital dying' is pervasive. There is considerable consensus among healthcare professions, academics and policymakers of the need for healthcare reform and further research on end-of-life care in hospital (Clark et al., 2015). The need to improve the safety and quality of people with life-limiting illness in hospitals is a matter of urgency and one that affects us all, and there is an imperative to investigate the use of innovative and diverse methodologies in this respect. Explanations for the problems associated with hospital dying are multiple and complex, and interrogating them is beyond the scope of this article. However, Iedema et al. (2013) have argued that the very complexity of our healthcare organisations, along with the extraordinary frequency of change and the associated disruption, can render knowledge gained by conventional research methods alone obsolete or irrelevant before it reaches frontline care. As Corner (2015, p 2) posits, 'We have poured linear compartmentalised knowledge into complex connected systems and have been repeatedly frustrated by the results'. He argues instead for strategies that would help connect people, ideas, knowledge and practice. In other words, they would transcend what McCormack (2011) refers to as the false boundary between the use of knowledge and its production, whereby knowledge is regarded as 'unproblematically separable from the scientists who generate it and the practitioners who may use it' (Greenhalgh and Wieringa, 2011, p 503). An alternative view of knowledge is one that encompasses spiritual, community and tacit knowledge and recognises the multiple perspectives of stakeholders in knowledge generation and use (Rycroft-Malone et al., 2016). This would mean the development of care organisations that integrate clinical research and practice to become what the Institute of Medicine refers to as 'learning healthcare systems' (Olsen et al., 2007).

In this article I will argue that video-reflexive ethnography (VRE) is a potential practice development methodology to facilitate the kind of healthcare environments espoused by the Institute of Medicine and Corner.

Drawing from the findings of my doctoral research, I explore the use of VRE as a practice development methodology to improve palliative and end-of-life care. The aim of the study was to 'investigate the links between the places/spaces where people who are dying are cared for and how these spaces constrain or enable their agency and contribute to the quality of care they receive'. In this paper I report what I refer to as the 'methodological findings' of my research. That is to say, I examine the role of VRE methods in end-of-life care research and practice development. More specifically, this article addresses the following questions:

What do collaborative, practice-oriented feedback and reflexivity approaches using visual methods contribute to practice development?

Can visual methods promote the stories of research participants and communicate principles and strategies to facilitate improved end-of-life care for people and their families, healthcare workers, service providers, administrators, designers, planners and policymakers?

Drawing from the practice development movement and its theoretical underpinnings, I propose the use of VRE as one potential methodology to facilitate opportunities to improve end-of-life care, as well as address concerns about it.

Practice development

Person-centred care, a key concept underpinning palliative and end-of life care, is defined as:

'An approach to practice established through the formation and fostering of therapeutic relationships between all care providers, people and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development' (McCormack et al., 2010, p 13).

By promoting person-centred care and explicitly striving for practice change and innovation, practice development aims to help frontline healthcare workers not only to look critically at their practice but, importantly, at how it might be improved (McCormack et al., 2009). With its focus on working with people, through collaboration, inclusion and participation (Trede and Titchen, 2012), improvements in care or person-centred care are achieved through individual and collective transformation (Manley et al., 2008). This kind of transformation encompasses diverse kinds of knowing, including practical and creative wisdoms. It requires what Manley and Titchen refer to as 'professional artistry', encompassing bodily, emotional and spiritual knowledge (Titchen and Higgs, 2001; Titchen and Manley, 2006).

Thus through practice development, the knowledge of frontline workers and also, I would argue, patients and families, is co-produced with knowledge of academe (McCormack, 2011). Practice development is therefore consistent with the Institute of Medicine's 'learning health system' approach; it embraces creative, affective and relational as well as cognitive ways of knowing (Trede and Titchen, 2012) to explore ways of being and working that are often taken for granted. I looked to VRE to explore these 'taken for granted' aspects of care.

Video-reflexive ethnography

VRE is a collaborative methodology involving researchers and/or participants filming participant accounts of care and/or care interactions, and analysing visual data together (Iedema et al., 2006, 2013; Wyer et al., 2015). It requires the researcher and/or research participants to gather visual data of accounts of care and/or practice (V), analyse and make sense of the data together with participants (R), and can include a diverse range of research methods to explore and understand people's experiences of care and how that care unfolds in practice (E). Here, reflexivity extends beyond individual reflection – it is 'collaborative in nature, diffuse in focus, open-ended in purpose and immediate in effect' (Iedema, 2011, p i84). Consistent with a practice development approach (McCormack et al., 2013a), VRE explicitly seeks better understanding of the complexity of healthcare delivery and how that healthcare is enacted in situ, and through this new understanding attempts to improve care delivery from the 'bottom up' (Iedema et al., 2013).

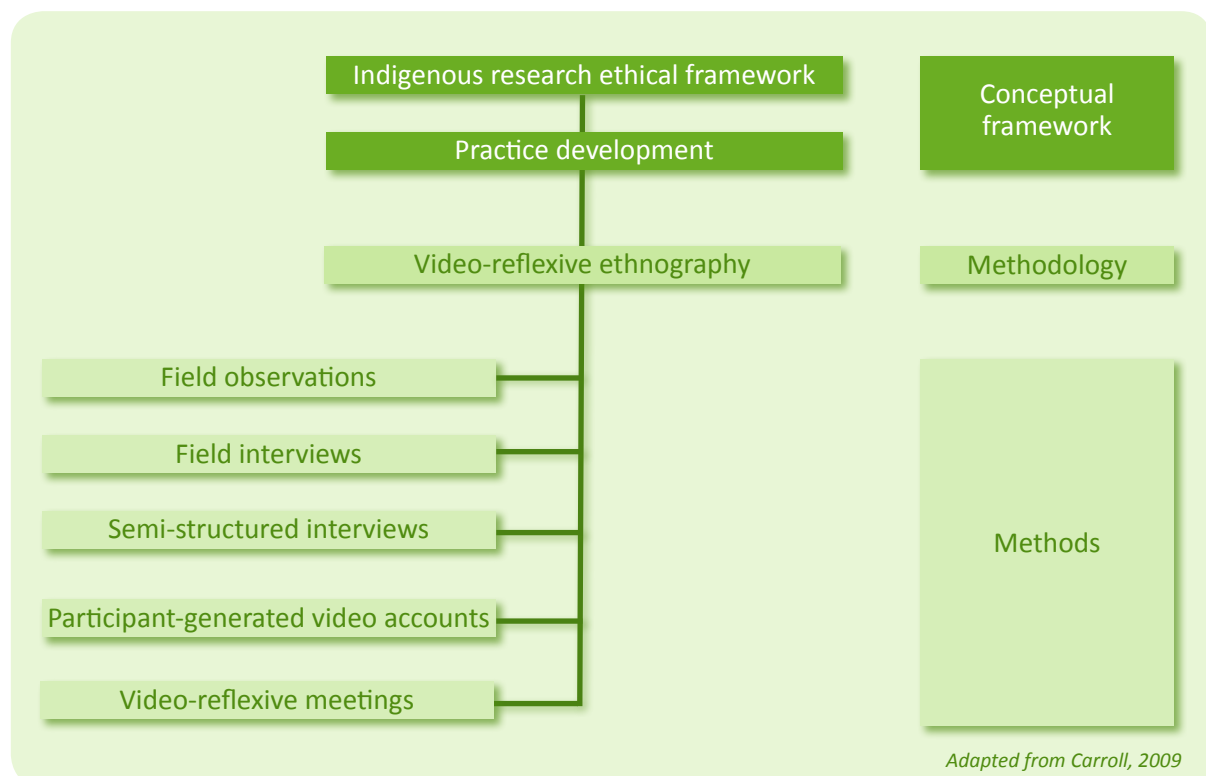
By watching footage of themselves and/or those they have cared for, healthcare workers are often able to see aspects of themselves and their practices that they may have learned not to see (Iedema et al., 2009). In other words, 'taken for granted' ways of being become second nature, and seeing footage can reveal habitual ways of being and working that they had not been aware of (Carroll et al., 2008). This different way of seeing can potentially move practical wisdom into consciousness (Iedema et al., 2009), bringing to the fore the implicit aspects of safety and quality, or what Mesman (2007) describes as 'resources of resilience'.

Ethical considerations

As a consequence of regarding the boundary between knowledge use and production as false in the way described by McCormack (2011), I came to regard the boundary between the researcher and the researched as a false one. In doing so I acknowledged ethics and epistemology as inseparable, viewing the research not as approaching problems to be solved but as addressing questions to be lived (Collier, 2013). While the study received institutional ethical approval, in my view this did not go far enough. Given that I was researching patient safety and end-of-life care with people who were dying and their families, as well as with those caring for them, I considered it of critical importance that the research itself avoided rendering spaces emotionally, psychologically, spiritually or physically unsafe. Furthermore, previous studies exploring what is important to patients and families towards the end of life have highlighted that people wish to be treated with respect and have their experiences and views recognised in reciprocal relationships with care providers (Steinhauser et al., 2000). Most critical is that the way people are viewed by healthcare workers influences whether or not they feel treated with dignity (Chochinov, 2004). How then, as a novice researcher, could I justify treating people as data and/or breaking them down into 'codes' to meet the academic objective of my dissertation?

I was inspired in my ethical approach by an indigenous research ethics framework. The central aim of indigenous methodologies is to ensure that research is carried out in a manner that is respectful, ethical and participatory, with researchers seeking to view the world from the perspectives of indigenous peoples (Botha, 2011). Of the utmost importance to indigenous scholars is connection with each other and a world viewed in spiritual and physical terms (Mertens, 2009). This translated as a need for me to try to see the research from the point of view of participants. Thus, I actively sought to position people as agents in the research, taking a reflexive approach (Collier and Wyer, 2015). Furthermore, this approach allowed me to attend to intuitive, spiritual and personal ways of knowing (Bishop, 2005). That is, I endeavoured to make connections with people and develop relationships and reciprocity, seeking out people's agency, and working with that agency rather than selecting a pre-determined methodology and fixed set of methods (Collier, 2013).

Figure 1: The relationships between the ethical framework, practice development and VRE



Method

I describe study methods, including how I approached ethical decision-making in situ, in detail elsewhere (Collier and Wyer, 2015). In this paper, I provide a summary outline of the process of VRE in Table 1.

Table 1: Video reflexive ethnography	
VRE phases	Level of analysis
<i>E</i>	<i>First-level analysis</i>
1 Ethnography: semi-structured interviews, field observations, field interviews, shadowing of healthcare workers (medical, nursing, allied health and ancillary staff)	<ul style="list-style-type: none"> • Coding and development of key themes by the researcher • Each dataset informed the others in a systematic, continuous comparison within and between datasets and through the lens of how patients and families talked about patient safety
<i>V</i>	<i>Second-level analysis</i>
2.1 Negotiated filming of people's accounts of care and/or practice (patients, families, clinicians and ancillary staff)	<ul style="list-style-type: none"> • Reviewing of footage with participants who are the subject of footage (if they wish) and/or seeking their consent to share footage with others, including negotiated decision-making about to whom and where to present footage
2.2 Editing of footage by researcher and/or together with participants according to their wishes and according to themes arising from all datasets	
<i>R</i>	<i>Third-level analysis</i>
3 Reflexive viewing of narrative-governed, themed clips for collaborative discussion (three- to six-minute clips that represented themes across all datasets and negotiations with participants to show them to one or more of the following: individuals, small groups or larger groups)	<p>Feedback of footage to provide immediate critique of researcher-derived themes by asking the following questions:</p> <ul style="list-style-type: none"> • What does the sequence say to you? • At whom do you think the footage is directed? • Is there anything that is 'hidden' that the footage doesn't tell? If so, what and why? • What is your role in patient safety and quality of care? <p><i>Adapted from Gibson's (2005) 'movie method'</i></p>

In this paper I focus on what I call the methodological findings associated with the reflexivity (R) component of VRE and in relation to the philosophical approach to the research and my approach to research relationships that I have described thus far. My description of methods here is focused on the third-level analysis of VRE and foreshadows my discussion of findings. That is, I explore the effects of inviting participants themselves to become involved as stakeholders in the research process by involving them in the process of analysis through the viewing of participants' (including patients', families' and healthcare workers') accounts of care. Although collaboratively produced knowledge and action often unfolded within the context of structured video-reflexive meetings, these were inseparable from and only in context of the relationships and approach to the research I have so far espoused.

Working with patients, families and healthcare workers, I provided opportunities for initial analysis of participants' own individual footage should they wish to review it and select particular clips for the purpose of showing others in video-reflexive meetings. In preparation for showing footage to key stakeholders, I edited it into narrative-governed, themed clips. This initial analysis took account of other ethnographic data, including field interviews, audio interviews and field notes so that these

clips might, to some degree, represent the voices of those participants who had opted not to be filmed. I aimed to select footage that demonstrated the differing perspectives of patients, families and healthcare workers. In addition, I considered whether or not footage might provoke discussion and debate. Footage selected for any particular group depended on the audience and the amount of time I was allocated. The process of editing and deciding which footage to show was never straightforward and I applied my own ethics and drew on my clinical experiences as a nurse in seeking to portray a balanced view of selected clips (Collier, 2013). There were three styles of video-reflexive meetings:

Small group meetings

Four meetings took place in the acute hospital at times negotiated with individual groups and usually coinciding with already structured timeslots such as departmental 'journal clubs'. These meetings resulted in additional invitations to facilitate groups from within and outside the research site. For example, a meeting was requested by and run specifically for the cancer therapy centre frontline administration healthcare workers. In these meetings I showed up to three short film clips, each up to six minutes long. When facilitating these meetings I began by providing a brief background to the research, and positioned the clips within the wider analytical context of other ethnographic 'data' collected as part of the research. I invited participants, as key stakeholders in the research, to respond to the screened clips, saying how they felt about what they saw and heard. I prefaced the screening of clips with the questions adapted from Gibson's (2005) 'movie method' (Table 1).

One-to-one meetings

I offered medical specialists involved in the care of individual patients and family members who had participated in filmed interviews the opportunity to engage in a one-to-one meeting to review footage reflexively if they consented to doing so as participants in the study. With one exception, all specialists (a total of nine) accepted this invitation. One-to-one meetings were inclined towards a more informal conversational-style dialogue than the group meetings.

Large group meetings

Invitations from larger groups at the acute hospital research site, as well as external groups, were numerous and fell into the following categories:

- Healthcare community. Several other metropolitan hospitals as well as the field site provided the opportunity to present at their 'grand rounds' or equivalent forums
- Policy related, including the executive of the national framework for quality improvement of specialist palliative care
- Professional bodies, such as state palliative care institutions for presentation to their membership
- Educational forums. The presentation was used as the focus for a workshop to set up a hospital-wide generalist nurse resource programme at one of the satellite field sites in collaboration with healthcare workers
- Consumer groups. Carer groups used example narrative vignettes as a focus for discussion about informal carer strategies when caring for someone who is dying
- Research community. Footage was used as the focus for dialogue and critique with service providers and academic peers (Collier, 2013)

I sought explicit consent from individuals who were the subject of clips for their use in these larger meetings and experimented with their structure, depending on their size, who the key stakeholders of the meetings were and how much time I had been allocated. I asked organisers to provide roving microphones so audience members could be invited to respond in the same way as the members of the smaller groups, even when there were as many as 100 attendees.

Findings

In this section, and drawing on data from my doctoral research, I analyse the part played by VRE methodology in bringing forth knowledge through the kind of creative collaborations I sought to engender. In so doing, this part of the article highlights the reach of video within and beyond the study and includes the following themes:

- Video: making hospital dying tangible (internal stakeholders)
- Video: making hospital dying tangible (external stakeholders)
- Video: a camera eye
- Video: producing legacy

Video: making hospital dying tangible (internal stakeholders)

Small group reflexive meetings revealed how people's visual narratives could make tangible what was otherwise intangible in everyday practice. These meetings created a space for healthcare workers to consider ways of being and doing in end-of-life care. The localised meaning given to the footage provided an impetus for exploration of alternate ways of being, thinking and acting. In the extract that follows, a member of staff from the radiotherapy department reflects on relationships with people under their care:

'It's hard not to give too much because you'll wear yourself out but give a bit of yourself to feel like it's not just you inspecting a person or talking to a person, it's actually give and take, it's two human beings interacting not a uniform interacting with a patient, and that, I think, came across there as much as with the two gentleman [in consumer advisory group] we spoke to over the past couple of weeks. It's back to personalising the care' (Small group reflexive meeting, acute hospital, cancer therapy centre).

For the healthcare worker quoted above, footage affirms how positioning someone receiving care as another person, rather than a patient, requires removal of a 'professional mask'. These group meetings were not viewed in isolation to other service development matters, however, as this participant connects what she sees on the film to other recent experiences and perspectives.

People within the context of reflexive meetings began to see opportunities for action. In the next extract a service director compares and contrasts the care in outpatient and inpatient settings in the context of the kind of person-centred care raised in the quote above. The director proposes 'workarounds' to negotiate organisational bureaucracy:

Service director: 'But there's a whole lot of differences between outpatient and inpatient care. I think inpatient care is more protocolised. It's more sterile just by its nature and I've been reflecting on this when listening to this about the design of the hospital. It's very protocolised. So you get presented with what a bed looks like and the bed doesn't have anywhere for photographs or room to move with regard to any paraphernalia around the bed because the Department of Health standard code is "that" and even when I heard about your research and suggested that we might have input into the painting it was like I created world war three.'

Researcher: 'Yeah?'

Service director: 'Yes, because the reaction was "no". A committee decides that. You know, like a committee decides the colour of the paint.'

Researcher: 'I mean, I have to say I didn't really know how to respond to your email.'

Service director: 'Well no, in actual fact, I achieved what I wanted to, which was to cause a little bit of agitation and then I'll pull my head back in now and just let things happen. They'll paint it any damn colour they like and then once we take the space over and have a little bit more free rein then I think we go in and make some changes. Now, I've got some changes planned. I don't have all the changes planned because I'd like input from lots of other people and I think we have the possibility of doing that in the new palliative care ward' (Small group reflexive meeting, acute hospital, cancer therapy centre).

This extract shows how footage stimulates the service director to interrogate the 'taken for granted' view of a hospital bed and the possible role of hospital regulations in preventing personalisation of the bed space. The reflexive session prompts examination of why person-centred care is more possible in the outpatient setting, including peoples' connections with healthcare workers, the routinisation of care and the role of the built environment in facilitating person-centred care.

Despite the level of seniority of the clinician quoted above, the extract shows how they still felt bound by governing processes for planned redesign of the cancer centre. This medical specialist, however, took the opportunity to attend a number of meetings, engaging with the researcher and research more broadly as service lead and using the research process to their own advantage. This clinician is to some extent prepared to go along with usual regulatory processes yet also articulates strategies to work around these processes in order to facilitate an environment more conducive to person-centred care. In the space offered by reflexive meetings, ideas and creative solutions were put forward, as the following extract from a group session with the cancer centre administration team shows:

'Why not have more volunteers and you've got people, you've got a ward with four sick people in there. Why not have volunteers there all the time, you know, they've got someone there all the time' (Small group reflexive meeting, acute hospital, cancer therapy centre administrative staff).

Administrative healthcare workers in the extract above use the meeting as the means to generate possible solutions to what they see as the need for patients to be able to connect with others while in hospital. Critically, with the camera acting as mediator, group reflexive feedback meetings could reveal what was 'lost from sight'. In the next extract, the footage makes the otherwise invisible visible to administration workers, prompting a proposal that it be shown more widely:

Participant 1: 'Should more of these videos go around? I don't know – what would you say? Right around the whole hospital? Every department where nurses and admin and allied health are all viewing this and actually seeing the other side?'

Participant 5: 'The hierarchies. They should be seeing it' (Small group reflexive meeting, acute hospital, cancer therapy centre administrative staff).

These group members saw themselves as being particularly limited in their ability to influence care. Their use of the term 'the hierarchies' to describe managerial staff and senior administrators of the hospital is perhaps indicative of how removed they felt from this level of the organisation and from 'having a say'. People in all reflexive meetings and at all levels, including professional and non-professional staff, suggested that footage be shown to senior administrators in their organisation. They also frequently requested that I show the vignettes to politicians. They saw this as a means to advocate for patients and for themselves, especially in forums where they considered that people with political power who were capable of influencing care were present. Participants also, to a large extent, saw footage as a critical opportunity to make tangible the 'extraordinary' work that they do in caring for people nearing the end of life.

One-to-one reflexive meetings included respiratory specialists, surgical as well as medical oncologists, radiation oncologists and haematology specialists. All those who participated articulated how much they valued the opportunity to view care through the lens of patients and families. Without exception, however, they also conveyed their anxiety about being confronted with patients' and families' views of their care. Mediated by video, these senior doctors were able to identify closely with patients' and families' narratives as well as those of other clinicians, and with the practice-related events in these stories. The video narratives had a profound impact on these doctors; without exception, specialists spoke of 'being moved'. For example, they were struck by how starkly the footage made them aware of people's proximity to death. Through the medium of video, healthcare workers were able to see and relate to the care environment from the perspective of the dying person:

He [staff specialist, oncology] choked up with tears and quickly pressed the space bar to pause the footage. After giving him a moment, I asked: 'What is it that has touched you?' 'Well it's that he is in such a noisy, terrible environment in a four-bedded bay, when at the very least, I would expect, for me, to be in a single room several days before I die. But he is more concerned about us, us healthcare workers, not himself. He's expressing his understanding and empathy for us, and it's just a few days before he died' (One-to-one reflexive meeting, acute hospital, staff specialist).

Being close enough to be able to connect closely to the relationship and care-setting, yet far enough away to see it from a different angle, not only brought to light the significance and effects of the care environment of the hospital but helped healthcare workers see their own actions from a different perspective, even when they were not the subject of the footage:

'Then we [medical team] sort of come in and blast something out in five minutes and say right everything good, any questions, so goodbye and it's nice to see you. I mean the patient is there for the rest of the day and that night just to sort of ponder and think about that experience, whereas we've then left and moved onto the next patient and so it's interesting you know just to look at the world from their point of view. It would be interesting to lie in a hospital bed for 24 hours and see the nursing staff running around and going crazy' (One-to-one reflexive meeting, acute hospital, staff specialist).

The specialist quoted above reflects not only on what the view of the person they are caring for might be in the context of dying but also what the experience of being a nurse might be like.

The research produced additional 'spaces of engagement' beyond the individual and group meetings at the site of the research. Filmed narratives acted as a kind of affective connector between various different stakeholders. The following section looks at these 'external' reflexive meetings.

Video: making hospital dying tangible (external stakeholders)

External stakeholder groups, unlike healthcare workers participating in reflexive meetings at the research site, did not 'know' the participants. Despite this, these audiences were able to identify with the circumstances and people in the footage. They connected 'affectively', because people they viewed and heard on screen and with their situations resonated with their own contexts and experiences of end-of-life care:

'The problem is, as palliative care healthcare workers, once again end-of-life care is not just the responsibility of palliative care. Somehow we [specialist palliative care community] need to get other services to take this on. It [improvement in end-of-life care that takes account of patients' and families' experiences] not only needs to come from down up; it needs to come from top down in terms of policy development. It does have to appear in NSAP [National Standards Assessment Programme]. It does have to appear in NSW Health but it needs to be a cultural change and so often palliative care is seen as the ambassadors for this, but we can't accept ultimate responsibility' (Large group reflexive meeting, service director, 20th Annual Symposium of the Sydney Institute of Palliative Medicine).

This extract shows how the footage provoked deliberations among palliative care specialists about their role in promoting better end-of-life care. Forums such as these resulted in further invitations at a policy level. For example, at an executive meeting of the lead national body for palliative care, the group debated quality measures for end-of-life care led by the filmed perspectives of research participants.

In these larger forums the research itself became the subject of controversy. For example, on one occasion an attendee expressed concern that I was complicit in exposing healthcare workers to unnecessary harm by provoking guilt for those employed in a 'broken' healthcare system. On another occasion, at a hospital 'grand rounds' event, a physician suggested that I had intentionally selected controversial footage aimed at rousing emotion. This accusation was accompanied by the suggestion that people's visual narratives were clearly not 'representative' of the majority of patients and families (Collier, 2013).

Deciding what will and will not upset participants or create controversy in any ethnographic research is not straightforward (Bosk, 2003). In both cases I reflexively considered my positioning along with participants. The meaning of footage is not fixed or independent of the viewer (Pink, 2007). I propose then that harm is dynamically and contextually defined; taking a position that harm may have been caused assumes that these healthcare workers do not have resources and agencies to respond to footage. There is, however, an alternative perspective and that is the possibility that the very emotions – offence and vulnerability – provoked by the footage may be necessary to unsettle habitual ways of being and responses to the world (Dewey, 1922; Tamsin, 2005). Rather than being problematic, promoting offence may in fact have positive effects, or as the senior surgeon puts it:

‘Well I think clinicians need to see these sorts of footages. If we don’t, or if we decide not to, it means we are avoiding something because we feel a bit vulnerable, so we’re not actually facing up to how we are actually perceived by the people that we treat’ (Large group reflexive meeting, acute hospital staff specialist).

Video: the camera eye

There were other effects of embedding myself along with the camera within the specialist palliative care team in the acute hospital that I had not anticipated. It was not unusual for members of the team to say in their care narratives ‘I wish you were there with the camera when...’ An example is the following extract from a conversation with a palliative care staff specialist relaying a consultation with a patient in clinic:

‘I wish I had had the camera today. You know, I was sitting there [in clinic] and thinking, what else is the patient going to say? And it was 45 minutes and the next patient was waiting. The patient said, “You know if it wasn’t for palliative care I think I would be dead by now. You listen and you fix things. You know I haven’t spoken to anyone else like that before”.’ (Field Interview, acute hospital staff specialist, palliative care).

Specialist team members came to view their day-to-day work through the lens of the camera. The specialist quoted above, by envisaging the camera’s presence in the clinic, is somehow able to see an outsider’s perspective of their dialogue with a person. On this occasion their motivation is the desire for other healthcare workers to understand both the needs of a person with a life-limiting illness and the role of specialist palliative care providers. This ‘third-eye’ camera view continued beyond the duration of my fieldwork and was applied in various contexts and settings.

Video: a legacy

Video created a means for people who knew they were dying to impart something of themselves that would continue beyond the conclusion of their earthly existence. Filmed narratives transcend time, offering a means for those people to continue (Collier and Wyer, 2015). For example, George expressed a wish to leave footage behind for his grandchildren:

‘I [researcher] bumped into George with the hospital palliative care nurse sitting outside on the hospital wall. George expressed: “They’ve [medical team] given me bad news today and I am being transferred to [names palliative care unit]. I want to take part in the research. I want to leave something for my grandchildren”. I emphasised to George it wasn’t necessary to participate in the research in order to leave a filmed legacy for his grandchildren. But George was adamant. “No”, he exclaimed. “I want to do both, I want to take part in the study, but I also want to leave a direct message for my grandchildren. But not here [acute hospital]. Come and see me at [names palliative care unit]”.’ (Field interview, patient and palliative care nurse, acute hospital).

There was a moment when I was uncertain if I should interrupt George and the palliative care nurse. I had met George previously as I shadowed one of the junior doctors, so I decided to say hello. There

was an instant of closeness as all three of us connected in that moment in a way that is difficult to convey in words. Through the medium of film, patients and families conveyed their experiences and wisdoms. They hoped that their stories, made accessible, would help others facing dying and death as well as professional caregivers. Person-centred care from this perspective perhaps includes that person being able to contribute their legacy when they are no longer physically present. Preparation for a future they will not be part of and reflecting on their life lived is important to people with a life-limiting illness (Steinhauser et al., 2000).

Discussion

There is consensus internationally of the need for improved palliative and end-of-life care in hospital settings. What is less understood is how this might be realised in practice (Taylor and Chadwick, 2015). Researchers in the field of patient safety are increasingly recognising that compliance models, such as guidelines, protocols and care pathways, fall short in this respect (Jerak-Zuiderent, 2012). The complexities and uncertainties inherent in end-of-life care mean excellence in care requires focused attention to the 'whole person' and includes the emotional, social, psychological and spiritual as well as physical aspects of care (Sepulveda et al., 2002; Hutchinson, 2011). In unpredictable and complex care settings, tick-box approaches are of limited value (Braithwaite et al., 2015). This is highlighted in the recent debate and review of the Liverpool Care Pathway for the Dying Patient and its subsequent withdrawal from policy in England (Neuberger, 2013).

Perhaps of most significance is that the SUPPORT study authors later questioned if their research intervention had underestimated the human aspects of suffering and death at the expense of rational decision-making processes (Benner et al., 1999). Thus, I argue that there is an imperative for methodologies and creative approaches to complement conventional methodologies by acknowledging the relational, moral and ethical dimensions of death and dying (Collier, 2013) and accounting for healthcare organisational complexities to promote the kind of 'learning systems' I have described. I posit that VRE offers a potential practice development methodology to addressing the problem of dying in hospital.

What do/can collaborative practice-oriented feedback and reflexivity approaches utilising visual methods contribute to practice development?

With its regard for healthcare workers, as well as patients and families, as 'whole' people, and an emphasis on affective as well as cognitive knowing, along with the underlying values of mutual respect, VRE is consistent with the core values of practice development.

Drawing on an indigenous research ethics framework (Nicholls, 2009), I engaged multiple methods. In keeping with practice development, this was not with the aim of triangulating towards definitive certainties, but acknowledging collective wisdoms and creativity (McCormack et al., 2013a). In other words, VRE provided one way to facilitate the collaborative intertwining of the stories of patients, families and healthcare workers, including my own, resulting in the crafting and recrafting of new stories. This continual negotiating and renegotiating of relationships between researcher, participants and other stakeholders in the research is central to an indigenous research ethics framework and practice development. This was never straightforward and, as the findings show, introducing visual methods threw up additional challenges, requiring me to question my thoughts, actions and decision making, and to negotiate ethics not as a prescribed task to be done or procedures to be followed but as unfolding in practice (Clarke, 2012).

At one level, healthcare workers conveyed that they were not surprised by what they saw. They expressed feelings of being powerless to respond to what they considered safety and quality concerns beyond their control and/or articulated these concerns as the responsibility of a 'health system' discrete from them. Indeed, healthcare workers often conveyed their frustrations with what they regarded as organisational values more focused on financial, regulatory and political objectives than

on person-centred values (Titchen et al., 2011). Discussions arising from reflexive viewing of footage highlighted how healthcare workers often viewed the delivery of person-centred care as occurring despite organisational characteristics rather than because of them. Thus, any improvements in end-of-life care need to attend to organisational, cultural and political factors influencing safety and quality of care as well as individual factors (Bergenholtz et al., 2015). The theoretical underpinnings of practice development and VRE, rather than excluding these complexities, seek to recognise and even embrace them (Iedema et al., 2013; McCormack et al., 2013b).

However, VRE also produced a kind of disruptive innovation. Healthcare workers found the footage revealed patients' and families' understandings that they had not previously considered. Video narratives brought healthcare workers 'up close' yet created distance at the same time; that is, staff were able to identify closely with the people, stories and events in the clips while being sufficiently removed from them to pick up previously unnoticed aspects of their relationships with others, the care they provided and the hospital environment. This challenged their assumptions about in-hospital care of people at the end of life and their families. In other words, VRE can help people to see those they care for and their role in their care through a different lens. It appears to foster what Shusterman (2006) calls 'better somatic knowledge' and greater awareness to improve understanding and performance (Shusterman, 2006, p 13).

Can visual methods promote the stories of research participants and communicate principles and strategies to facilitate improved end-of-life care to people and their families, healthcare workers, service providers, administrators, designers, planners and policymakers?

People with life-limiting illness are often labelled as 'dying hospital patients' and 'vulnerable' research subjects, and participants are often positioned as what Bishop (2005, p 110) describes as 'minoritised peoples'. Defining inclusion in research of people who are dying as unethical can mean they miss out on opportunities to gain knowledge that is useful to them and others (Agrawal, 2003). Research participants who were recipients of care frequently wished to share their wisdom with others, including healthcare workers and service providers as well other people experiencing care now and in the future. The preservation of this wisdom was made possible by the research, through being prepared to engage with others on their terms rather than 'boxing' them in to a particular way of contributing.

Thus, as researchers, I argue that we need to be willing to let go of set notions and ideas about the research process and allow collaboratively determined and enacted methods to unfold. I argue for transformative research methodologies that foreground affect and the letting go of boundaries between self and other. I posit that only through this kind of approach is it possible to collaborate on negotiated terms with individuals – in the example of this study, with people close to death. This way of being resists fixed expectations, identities, practices and methodologies (Law, 2004). In this way VRE also promoted (and continues to promote) democratisation of the research findings to external stakeholders by opening up spaces for discussions about death and dying and end-of-life care.

Perhaps most difficult as the researcher is being willing to relinquish control, to become open to being transformed oneself. Yet, as researchers involved in practice development, surely we need to be open to being transformed as we work alongside others, attuning with those others and being open to alternative ways of thinking and perceiving, being and acting ourselves. In other words, we need to work authentically (Sanders et al., 2013, p 36). This way of researching is not straightforward as it requires the researcher, just like the healthcare workers, to be prepared to remove their 'professional mask' and to negotiate complex ethical questions and decisions as care unfolds in practice. Perhaps it is only by making ourselves vulnerable in this way that we enable experimentation and creativity. I propose that this way of researching may be achievable and that it may hold 'transformative potential' for both participants and researchers through the kind of 'professional artistry' described earlier, whereby collaborative and creative processes allow the research to proceed without knowing where it might go (Titchen and Higgs, 2001; Titchen and Manley, 2006).

Limitations

A significant limitation placed on the use of VRE was the necessity to define clear objectives to meet institutional ethics committee requirements rather than negotiating them with participants and thus enacting the indigenous ethical framework in the way I had hoped. Moreover, only those patients, families and healthcare workers who met research criteria, and those who elected to be filmed or attend reflexive meetings, had a voice. This meant that people who could not speak English or were cognitively impaired were excluded. Yet not excluding participants from the research, even if they preferred not to be filmed, ensured those people retained a voice in the study, for example through inclusion in the VRE analysis processes. There was also the possibility of representing participants in ways they did not expect or wish to be represented and/or continuing to represent them in such ways into the future. These ethical tensions require multilevel reflexivity (Collier and Wyrer, 2015).

Conclusion

If normalised practices for end-of-life care, and indeed other aspects of care, are to be confronted, I argue that developing awareness of habitual forms of being and relating are necessary. Furthermore, I propose that we require methodologies that recognise healthcare workers and researchers as people as well as patients and families. Such methodologies need to take account of moral, ethical, emotional and affective factors, as well as cognitive concerns. Video-reflexive ethnography provides one potential practice development methodology to promote opportunities as well as identify barriers concerning improved provision of person-centred palliative and end-of-life care. While this may of course be achievable using other practice development methodologies, VRE may be able to attune people to different ways of doing and being in a manner not possible with other methods. Like any practice development methodology, however, it is only as good as the underpinning philosophical, ethical and values framework through which it is applied, and the skills and aptitude of the facilitators.

Implications for practice

Person-centred end-of-life care is not available for all people or in all care settings. It may only be possible when, as healthcare workers, we not only see those we care for differently but also when we see our colleagues differently – and perhaps when healthcare organisations see their employees differently. Most significantly though, as researchers we also need to be prepared to see ourselves differently. Video-reflexive ethnography opens up possibilities to achieve these different ways of seeing for all involved. Its potential applicability to practice development extends beyond palliative care to a range of possible contexts and environments.

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