

Abstract

Specialist palliative care is a prominent and expanding site of health service delivery, providing highly specialised care to people at the end of life. Its focus on the delivery of specialised life-enhancing care stands in contrast to biomedicine's general tendency toward life-prolonging intervention. This philosophical departure from curative or life prolonging care means that transitioning patients can be problematic, with recent work suggesting a wide range of potential emotional, communication and relational difficulties for patients, families and health professionals. Yet, we know little about terminally ill patients' lived experiences of this complex transition. Here, through interviews with 40 in-patients in the last few weeks of life, we explore their embodied and relational experiences of the transition to in-patient care, including their accounts of an ethic of *resilience* in pre-palliative care and an ethic of *acceptance* as they move towards specialist palliative care. Exploring the relationship between resilience and acceptance reveals the opportunities, as well as the limitations, embedded in the normative constructs that inflect individual experience of this transition. This highlights a contradictory dynamic whereby participants experiences where characterised by talk of initiating change, while also acquiescing to the terminal progression of their illness.

Keywords: Cancer and palliative care, Death dying and bereavement, Experiencing illness and narratives, Quality of life, Narrative analysis

The transitioning of patients from one site of care to another is an important site of sociological enquiry, often revealing key interdisciplinary tensions, bureaucratic difficulties and interpersonal and inter-professional dynamics (Meleis, 2010). Healthcare transitions are frequently marked by a change in the place of care, the individuals providing care, and/or the goals of care (Kralik et al., 2010). In some contexts these changes can bring challenges to patients, carers and health professionals, such as heightened feelings of anxiety, loss of control or a sense of confusion (Broom, Kirby, Good et al., 2012; Gardiner et al., 2011; Kralik et al., 2010; Meleis, 2010). Such concerns may be heightened in the move from life-prolonging or curative-focused care (e.g. oncological contexts) to life-enhancing care (e.g. palliative care contexts) (Gardiner et al., 2011; Lawton, 2000; Meleis, 2010; Zimmermann, 2012). Present in these transitions to life-enhancing care are the social and normative forces that surround illness experiences. In particular, the move to palliative care challenges and repositions norms relating to futility and hope, as well as practices of resilience and acceptance (Broom and Kirby, 2013; Broom, Kirby, Good et al., 2013, 2014; Gardiner et al., 2011; Kralik et al., 2010; Larkin et al., 2007; Marsella, 2009). However, the pathways through which people come to palliative care and the tensions and dynamics involved in the transition from life-prolonging to life-enhancing care remain under-examined. In response, our concern here is to unpack patient experiences of the transition to specialist

palliative care, focusing on transition as imbued with cultural values and normative constructs around illness and dying.

Background

The problem of transitions to palliative care

Scholarly work in the social sciences over the last several decades has demonstrated that the experience of dying continues to be infused with complex social relations, cultural norms and ethical dilemmas (e.g. Clark and Seymour, 1999; Glaser and Strauss, 1966, 1968; Kellehear, 2007; Lawton 2000; Seale 1998). Of particular note has been the development of formalised, professional expertise around the end of life in the late 20th-century with the emergence of palliative medicine as a key field within the dying process. While definitions around palliative care are not always consistent (Hibbert et al 2003), in Australia specialist palliative care denotes the palliative services provided by multidisciplinary teams to patients who have a terminal condition (Palliative Care Australia [PCA], 2010). Furthermore, in both Australia and internationally, people with terminal illnesses are increasingly being cared for by specialist palliative care services (Clark and Seymour 1999; Connor 2009; Gardiner et al. 2011; Lawton 2000; McNamara et al. 1994). Specialist palliative care's emphasis on quality of life and pain and symptom management can be experienced in stark contrast to life-prolonging care

and/or previous potentially curative treatments (Clark and Seymour, 1999; Connor, 2009; Lawton, 2000). The growth and mainstreaming of palliative care has *both* significantly altered patient care within the context of disease progression, as well as adding significant complexity to service delivery (Clark and Seymour, 1999; Hibbert et al., 2003). These complexities include professional roles (i.e. what palliative care versus life prolonging care means in practice), relationships (i.e. who is leading care) and the timing of transitions (i.e. point of futility) (Broom, Kirby, Good et al., 2012, 2013, 2014; Hibbert et al., 2003; McNamara, 2004).

More recently, the clinical focus has been on *smoothing* the transition to palliative care, through identifying the barriers to a ‘successful’ transition from life-prolonging to life-enhancing care, in order to reduce any sense of division between life-prolonging and life-enhancing care (e.g. Gardiner et al., 2011; Hibbert et al., 2003; Jarrett, 2009; Kralik et al., 2006; Larkin et al., 2007a; Marsella, 2009; Meleis, 2010; Patrick et al., 2007).

One consequence of finding ways to optimise the transition (Gardiner et al., 2011) has been to over rely on positive attributes, such as ‘resilience, reconstruction, coherence, life purpose, sense of self, transcendence and transformation’ (Larkin et al., 2007b: 87), to define a successful move. Further, such approaches have lacked consideration of the social and existential complexities of the emotional content and embodied experience of dying (Clark and Seymour, 1999; Larkin, 2007a&b; Lawton, 2000; McNamara, 2004).

While practical issues such as communication have been identified as complicating the move from life-prolonging to life-enhancing care (Gardiner et al., 2011; Jarrett, 2009; Marsella, 2009; Patrick et al., 2007), less attention has been given to the social norms, relational networks and embodied experiences that may problematise a person's transition. Put simply, how social and normative relations shape care transitions are not well understood.

A changing ethic of care for the end of life

The multiplicity of factors affecting the move from life-prolonging care to life-enhancing care each bring with them ideas of what is the 'right' or 'best' way to manage the end of life; or, what can be described as an *ethic of care* (cf Foucault, 2005; Gilligan, 1993; Mol, 2008). That is, the norms and discourses surrounding 'the good death' shape not only the experience of dying, but also, whether that experience is understood to be 'good' or 'bad', 'better' or 'worse'. For example, it has been argued that there is a risk that the dying process has become an extension of mainstream medicalised models whereby a 'good death' is one that is individualised, autonomously chosen, and is focused on a biomedically-reductive view of the dying body (McNamara et al., 1994). However, in the context of transitions to life-enhancing care the reduction of the experience at the end of life to such normative constructs limits how we might understand that move. Of particular significance in the transition from life-prolonging to

life-enhancing care is the relationship between resilience and acceptance (of dying). As is well recognised in the context of potentially curative or life-prolonging treatment, norms of resilience, fight, not giving-up, and maintaining positivity (particularly in the context of cancer) weigh heavily on patient experience (Aoun et al., 2008; Broom, Kirby, Good et al., 2013, 2014; Ehrenreich, 2009; Hogden et al., 2012; Nissim et al., 2009; Zimmerman, 2007).

Similarly, previous research shows that normative constructs frame the dying process (Zimmerman 2007: 302), including discourses around the critical juncture of denial versus acceptance (Zimmermann 2012: 223). While such analyses have proven useful in illustrating the ways care is situated within a complex array of normative forces, these same values of resilience and acceptance can also ‘open-up’ (cf Frank, 2010) new possibilities for people to experience their illness and address their lives at the end of life (Broom, 2009; Fullagar, 2002; Meurk et al., 2013). By focusing on the lived experiences of the contestations and negotiations involved in the transition to end-of-life care, the study reported here attempts to explore experiences shaped by resilience and acceptance to show how they both facilitate as well as restrict possibilities for people at the end of life.

Recognising embodied and relational subjectivities at the end of life

There is an established body of sociological work illustrating that the impact of illness (in this case, life limiting illness) goes far beyond the physical body and involves managing challenges to the individual's biography, ethos and subjectivity (e.g. Bury, 1982; Frank, 1995; Turner, 2008). As such, the norms and discourses discussed above about how to live and how to die are in turn problematised by the relational and embodied dynamics through which they are experienced (Broom and Kirby, 2013; Frank, 1995). This means medicalised approaches to pain and symptom management in the experiences of dying need to be augmented within a relational ontology that emphasises the interconnectedness of those who are dying with not only their carers, but also with their health professionals (Broom and Cavenagh, 2010; Broom and Kirby, 2013; Chattoo and Ahmad, 2008). Therefore, the analysis presented in this paper focuses upon how the move from life-prolonging to life-enhancing care is experienced through an embodied relationality that, hitherto, has been underexplored.

Methods

The qualitative study explored palliative care in-patient experiences, focusing on those within the last few weeks (or in some cases months) of life. The study was conducted in a short stay inpatient specialist palliative care unit, which was part of a sub-acute care

hospital that also had an attached specialist community palliative care service. Ethics approval was granted by the lead author's university human research ethics committee and the ethics committee of a specialist palliative care unit. Participants were first approached by their treating clinician, who provided an information sheet and – if the participant agreed – contacted the university researcher. The criteria for recruitment were that the participant had to be an in-patient on the specialist palliative care ward, be cognitively able to undertake an interview (i.e. achieved a score of >23 on the Mini Mental State Examination) (Tombaugh and McIntyre 1992), not be in significant pain, and be capable of providing consent. It should also be noted that these participants mostly had, at the time of interview, high palliative care needs requiring an inpatient stay. Patients that were interviewed had been admitted to an inpatient unit that has approximately 700 admissions per year with a death rate of about 60 percent.

A total of 44 inpatients were approached to take part in the study and 40 in-depth interviews, ranging in length from ten minutes to one hour and fifteen minutes, were successfully completed. For several participants the interviews were brought to a close early to avoid distress or because of the onset of tiredness or pain. A purposive sample was used to ensure that the participants reflected patient populations found in specialist palliative care in Australia (AIHW, 2013; Mitchell, 2011). As such, eighty-six percent of participants were diagnosed with advanced cancer and 54% of participants were

female. Ages ranged in frequency from one under 30 to one over 91 years old and the average age being 68. Twenty-one were married, five were divorced, six were widowed, one was in a *de facto* partnership, one was in a same sex partnership, and two were single (never married). Of those participants known to have died post-interview the median days survival was 23, ranging from one day to 112 days.

All interviews were digitally audio recorded and fully transcribed. The interviews were semi-structured and sought to cover, when appropriate, four key areas of the patient's experiences of in-patient specialist palliative care, including: reflections on their illness and time before admission; how they came to be an palliative care in-patient; what location they preferred to be cared for in and where they had considered dying; and, their personal and existential reflections on illness and dying. A dialogical interviewing approach was used to probe for detail and ask questions as the interview progressed (Frank, 2010). This provided the participant the space and support to explore the issues as they felt comfortable to do so. The interviews often raised sensitive and emotional content. At these times the interviewer sought to reassure the participant that they could pause, stop or withdraw from participating in the study. Participants were also provided the contact details of the hospital's counsellor when it was thought appropriate.

Interview techniques appropriate to the palliative care setting were used (Gysels et al., 2008, Steinhauser and Barroso, 2009). The interviewer sought to build rapport, develop

trust, and provide the participant with the time to reflect (Steinhauser and Barroso, 2009). Feedback provided to the researcher and clinical staff was that the experience did not generally inconvenience the participants, with many reporting that the experience was even pleasurable and positive. The interviewer was also given opportunities to debrief and reflect throughout the research.

Analysis

The methodology for this analysis sits within the interpretive traditions in sociology (cf Silverman 2011). Participants were treated as providing ‘socially competent’ understandings of their experiences (cf Giddens, 1991). From this starting point, the accounts were then explored to draw out the underlying structures, practices and discourses that shaped participant’s understandings. This approach followed Frank’s distinction between ‘thinking with’ and ‘thinking about’ narratives (Frank 1995: 23). In practice, the analysis was developmental and started once the initial interviews were completed and transcribed (Frank, 2010). Each interview was read systematically to identify themes, patterns and issues. These would then be developed or challenged through reading of other interviews and in discussion with colleagues. As the analysis developed the authors would go back over transcripts and notes to compile similar, atypical, conflicting and contrasting examples. Consideration was given to ensuring the complexity of participant’s experiences was not subsumed within analytical or writing

concerns by maintaining the data's centrality in any analytical discussion. As themes and issues emerged from the data they coalesced into related groups and sub-groups. Their intra and inter-relatedness were then examined via a critical and systematic re-engagement with the data. At these later stages the relevant literature was revisited to explore possible conceptual tools that would help to elucidate and make sense of the issues raised in the data.

Results

'Palliative care equals dying': Expectations of palliative care

The interviews were focused on exploring the patients' experiences of transitioning to specialist palliative care and their accounts of the embodied and relational underpinnings of this process. That is, what emphases, framings and relational influences were evident throughout this movement from life-prolonging to life-enhancing care. The transition between the two was not unproblematic for the majority of participants and involved a number of overlapping and competing expectations, including those around what palliative care means and the best time to initiate the transition. Despite a sizable body of research into the benefits of early access to palliative care (e.g. Ferris et al., 2009; Temel et al., 2010) and use of strategies that seek to introduce the benefits of the speciality to their patients (Gardiner et al., 2011; Temel

et al., 2010), palliative care still held negative connotations for many patients in this study. The following participant explained what palliative care meant for her:

P: I was scared of it [palliative care].

I: Tell me a bit about that, why you were scared?

P: Mmm. Dying.

I: Right.

P: Palliative care equals dying.

I: Right.

P: That's it. (White Australian, female, 31-40, ovarian cancer)

This participant had explained how she was caught between a desire to cease curative treatment and her fear of palliative care. Even when participants recognised the need for a space away from the exhaustion of the curative frameworks, it was not always possible to move towards palliative care. As well as the negative connotations and expectations of what palliative care might mean, the impact of palliative care on carers was talked about as leading to resistance and pressure to not engage palliative care. As another participant explained her husband '... doesn't feel that I should be here now'. She went on to say,

P: I don't think he fully understands that, the meaning of palliative care. And I don't think he appreciated how much I needed a rest, just to get away from things at home. And he himself needed some respite, without admitting it. He won't admit it. He needed some respite, yep. (White Australian, female, 61-70, pancreatic cancer)

As well as questions about what palliative care is, approaching palliative care can involve relational dynamics including managing the emotional expectations of others, such as carers, family and healthcare professionals. Indeed, several participants explained how a 'dysfunctional' relational dynamic with their doctors affected their gradual shift in focus away from curative or life-prolonging options. Returning to the first respondent discussed above, she explained how she had asked her oncologist for an estimate of how long she might have left to live, but for a long time he refused to discuss her prognosis with her. Eventually he provided an estimate of three months, which left the respondent 'blown for six'. Another participant similarly explained,

I: And so when you were having, when you were seeing this oncologist, did he ever talk about palliative care?

P: The oncologist? Heavens no. That would be against his business wouldn't it?

I: Yeah?

P: I can't understand him, now I know, I can't understand why he didn't help me in that way. I mean he could have sent me in here [SPC hospital], couldn't he?
(White Australian, female, 81-90, breast cancer)

The expectation that the palliative care of a patient is against the oncologist's 'business' reflects a tension between life-prolonging and life-enhancing strategies of care that was perceived to exist by some participants. It is possible that the resulting confusion and perceived exclusivity of these two pathways mirrors a difficult dynamic in the field whereby palliative care practices have increasingly been mainstreamed, at the same time as efforts have been made to demark a professional specialisation of palliative care (Hibbert et al., 2003). The resulting 'crisis of definitions' means that what is meant by palliative care and how it is delivered is therefore relationally dependent (Hibbert et al., 2003: 287). In the following excerpt, from a participant given a terminal diagnosis, this meant that palliative care became more associated with finding easier ways to die and less about quality of life issues.

P: . . . I will say to you I didn't know what palliative care was. My thoughts of what palliative care was that it's when you're going to die they sort of make it a little bit easier for you. That process of course I had no interest in it, because I

wasn't, I thought, willing to suggest that I was going to let go that easily . . .

(White Australian, male, 61-70, lung cancer)

Another participant similarly explained that he 'rebelled against this [palliative care], because I couldn't understand its meaning or purpose. It was absolutely foreign to me, completely'. For those participants with no prior knowledge of palliative care their sudden transition to it tended to invoke fears long associated with palliative care, such as ideas of 'giving-up' and discursive framing of palliative care as a way for clinicians to (quasi-legally) help their dying patient have a quicker death. As a consequence, many participants described how the complexity they faced allowed them to re-engage their treatment under a discourse of resilience, while also being resistant to any move towards palliative care as an end of life strategy. This resulted in many participants initially perceiving palliative care to be sitting outside of the curative-hope framework and, to a certain extent, found it to also be a challenge to that framework. Nonetheless, as we explore in the following section, for a number of participants experiencing palliative care raised questions about their life-prolonging treatment pathway.

'Being around a little longer': Extending resilience with palliative care

The majority of the participants were unfamiliar with palliative care when it was first topicalised by their doctor and thus their introduction to it was talked about as

producing feelings of anxiety and fear about what it meant for their life expectancy. In part to help mitigate such reactions the preferred clinical strategy is to ‘phase in’ the patient’s introduction to palliative care while continuing to receive technically life-prolonging treatment (Gardiner et al., 2011; Meyers et al., 2004; O’Leary et al., 2009). For several participants this phasing in of palliative care often helped to problematise experiences of the care and treatment the participant was receiving. For example,

P: Well, I want to carry on with the chemo obviously because I want to be around for a bit longer. I don’t really want to die just yet. But I mean I have to be guided by what the oncologist says because she’s the top of her field, Dr [Name], she’s one of the top people, and she’s very knowledgeable. And I think if she says to me ‘well look, there’s no point in us carrying on with chemo it’s not going to do any good, it’s just going to make you sick and your quality of life’s not going to be there,’ well then you’d have to accept that. But it would be very, very hard, because I’ve got a young, my youngest is just getting married . . . (White Australian, female, 61-70, bowel cancer)

The use of palliative care is experienced here as part of making life more comfortable, as the participant seeks to prolong life for as long as possible. Yet the relational dynamic of ‘wanting to be around for a bit longer’ is qualitatively focused on the

participant's youngest child's forthcoming wedding and forms the basis of her 'bedrock of resiliency' (Nissim et al., 2009: 170). Hence, this participant recognises she is positioned between the desire to engage chemotherapy, so that she can live longer, and the recognition of the consequences of pursuing this course of action upon her quality of life. However, what we also witness within this excerpt is the participant engaging an emerging ethic of acceptance, which is already helping her to prepare to face palliative care as a life-enhancing experience.

The phasing in of palliative care not only brought into question participants' expectations of the future, but it also helped to question the fears and anxieties of SPC, as one participant put it, of being a place where 'you don't come out'. This participant went on to say that he was wary of being admitted when his oncologist suggested they would be able to help with his pain. While his experience of SPC is very much framed as extending his resilience, he went on to reflect,

P: But coming here on Tuesday was a little bit of a push because, and I had to make sure I got over that psychological thing. But in retrospect I knew I needed to do something, and thought better to do it now whilst - I'm not well, but I'm well enough to accept it. Get in and have a look around, and potentially get comfortable with the surroundings. If I end up back here, which I don't want to

end up back here. That if have to come back, at least I've been here. I know the place . . . (White Australian, male, 51-60, gastric cancer)

Other participants similarly made the distinction that the aim of their current admission to specialist palliative care was to find a better form of pain management, rather than as part of an end of life process. The transition to palliative care was initially understood as finding ways to remain resilient within a life-prolonging framework, with palliative care providing the necessary pain and symptom relief to continue with life-prolonging options. However, the majority of participants talked about how these admissions helped them develop positive views on what was possible in specialist palliative care – in the context of life-enhancement – should they need to be admitted in the final days or weeks of life. As one participant explained, once she had experienced specialist palliative care, 'they've made me feel assured, like in this situation, if I need to come back, that I can. That you know, I feel comfortable coming back, that there's not an issue there. It's not an issue.' Therefore, emerging within these experiences of extending the participant's capacity to be resilient is an ethic of acceptance that problematises the trajectory that the (dying) body is on, but also helps participants become 'comfortable' with that. Coming to recognise the dying body, and the emergence of an ethic of acceptance that is associated with that, are the focus of the following two sections.

'After a while you just can't keep going': Toxic resilience

An important ethic within curative and life-prolonging treatment includes ideas of remaining 'resilient', not 'giving-up', and keeping a 'positive attitude' (Broom and Kirby, 2013; Broom, Kirby, Good et al., 2013, 2014; Ehrenreich, 2009; Nissim et al., 2009). However, as we have already begun to explore, the move to palliative care can disrupt previous notions, expectations and experiences of care and treatment. What was of particular interest here was how resilience within a potentially curative or life-prolonging focus became viewed as a problematic even toxic dynamic and counter-productive to maintaining or enhancing the participant's quality of life as they approached the end of life.

Coping with the persistent discomfort and pain experienced during the years of cancer treatment, for example, was not talked about as being without its consequences. As one participant explained, she had several forms of chemotherapy over a two-year period while pursuing a cure for her ovarian cancer. She then had radiation therapy, but she explained, 'Well, we don't know if it [radiation] didn't work because I didn't have a test because I didn't want to know anymore'. The participant said she had got to the point where she had ceased to have an interest in the outcome of her treatment. Reflecting on her treatment the participant went on to say, '...the pain has been pretty bad [crying].

But it's cancer, it's not a walk in the park is it? [sighs]'. Maintaining her resilience had taken this participant to a point where the effects of pursuing potentially curative treatments had become toxic not only to her body, in the iatrogenic pain she was experiencing, but also emotionally. Faced with this toxic form of resilience, she said she was only referred to palliative care 'When I stopped saying 'yes' to chemo'.

A large number of participants explained how they gradually became resistant to what they experienced as the ceaseless pursuit of a cure or life-prolongment in the context of their cancer in the form of an emergent apathy to the outcome of that treatment. Like the accounts of the above participants, their concerns then shifted towards the quality of life they had left. In doing so many participants drew not only upon the advice of their clinicians, but upon different bodily and relational resources to recognise that they had come to the end of this particular form of 'resilience'. For example, the following participant explained that she had extensive discussions about her ongoing treatment with her oncologist and palliative specialist. However, her decision to cease pursuing life-prolonging options was based not just on how she felt physically, but also on the relational support available to her from her husband. She explained her husband,

P: . . . would be there to support me, no matter what path I chose . . . He knew that there was only so much I could keep, keep taking in treatment. You know

after a while you just can't keep going. And I felt that I'd got to that stage.

(White Australian, female, 61-70, colorectal cancer)

Unlike the previous two participants, this participant had been receiving palliative care to help with her pain and symptom management. However, like the other participants above she explains that the recognition that her body had reached a 'stage' whereby further engagement with potentially curative treatments were futile, was recognised within the relational dynamic of her husband's support and the doctor's clinical knowledge. Highlighting the embodied relationality of the breakdown of resilience as an ethic, and the subtle but clearly present affect of coming to accept the dying body, again problematises how transitions to palliative care can be understood, something we return to in the discussion.

'I just accepted it': Knowing and feeling the right time to stop

Faced with the implications of remaining resilient, or what we have described as an *at times* toxic resilience, we found that several (but not all) participants engaged another (potentially) normative ethic in negotiating the transition to palliative care – that of acceptance. For example, the following participant described how she came to be aware that pursuing curative options was not going to be the way forward for her.

P: Look love, my body told me I couldn't take it. I took two rounds and just said to myself 'I know your body's telling you that you have to stop.' And I just accepted it and said 'well whatever I do' you know, and then these doctors, well they guilt you a little bit. They say 'you do realise that it's terminal if you don't do the chemo?' And I said 'I know, but I can't do it. I know my body is telling me I can't take it, can't take any more of that.' (White Australian, female, 51-60, cervical cancer)

The multiplicity of factors involved in the move to palliative care at the end of life is clearly evident here. The transition involves recognising the internally and externally-driven demand to remain resilient and pursue life-prolonging treatments. This includes the possibility that others – including family and clinicians – may not similarly recognise the futile pursuit of such treatments, or acknowledge that a new stage of illness is about to be embarked on and that there is a need to 'just accept it'. As with the participant who focused on subjective reasons for staying alive for her family for the basis of her resiliency, the above participant draws on her embodied reactions to chemotherapy to decide to stop. As Harrington (2008) found, there is a contemporary narrative whereby the person listens to a talking body; what she calls 'the body that speaks' (2008: 68). This is not to say that the subjective experiences in any way

invalidates the participants' decisions, but that they need to be accounted for in any understanding of the transition to SPC (cf Broom and Kirby, 2013).

Being resilient is an orientation many participants had identified with throughout the course of their illness up until the transition to specialist palliative care. As several of the participants discussed previously, letting go of this self-perception can be difficult. For example, the following participant described how she had lived a lifetime of resilience, from emigrating and struggling to survive in a new country, to bringing up a family in difficult times from wars to economic crashes. It might be expected that the participant would similarly understand her cancer diagnosis in these terms. However, she explained,

P: Yeah, when I went to see specialist, I decided before I go to see him, I tell my daughter-in-law, 'you know [name] this doctor cannot suggest for me have radium [radiation] or chemotherapy, I no want to have nothing like that. If it's too late, it's too late, I no want to go under the knife or under the machine, nothing like this.' I live long enough, I'm 82 years old, so what for you know, struggle, struggle maybe I say terrible but you know, struggle you know, in a lifetime it's not worth it. Better have a good life, healthy life, or not to have them.

I: So was that a hard decision to make?

P: Not for me. Somehow for me it feels and I think, I say “no, I don’t want to live like that, I better die.” No it’s not hard, not been hard for me. It’s been sad.

(White Australian-Hungarian, female, 81-90, lung cancer)

The ending of resilience within a life-prolonging experience can also mean the ending of established embodied and relational subjectivities of resilience. Acceptance does not necessarily follow, however for several participants it did provide an ethic that helped them to manage the complex embodied and relational consequences of moving from life-prolonging to life-enhancing care in ways that while difficult or ‘sad’, were seen as ‘better’.

Kubler-Ross (1969: 100) described ‘acceptance’ not as a happy stage, but as a void of feeling ‘It is as if the pain had gone, the struggle is over’. However, many participants explained that there was a sense of relief when they found somewhere that they could go that would help them in the final stages of life. For example, the following participant explained how specialist palliative care did not appear to hold any fears for him,

P: It didn't, not the way it was explained to me, it came across fairly positive.

“Oh shit, go somewhere where they're going to control my pain?” Yeah I'll take that! I'd be hitting that button all night, poor nurses! If you could rig me up to a box or something like they did and monitor me, yeah let's do it! Yeah to me, I thought it was the easiest road to take. (White Australian, male, 51-60, lung cancer)

For other participants the pain management in specialist palliative care contrasted starkly with the pain management they had received (if any) during their oncology treatment. That contrast meant that accepting the transition to palliative care was made a lot easier. Another participant described how her pain was poorly controlled while having her oncology treatment. Compounding this were the side effects she suffered from the pain medication she had been given, leading her to feel as though she was in a 'twilight zone' where she felt her only option was 'to literally dig myself down into a grave to try and get out'. The participant explained how this was 'the most frightening experience', that she was 'terrified' and felt that 'I couldn't get out of it'. But she also went on to say how 'things didn't really turn around until I started to come here [to SPC]' and how 'I just can't believe how lucky I am [to be in SPC]'.

The relief that many participants described when accepting palliative care at the end of life was therefore more than just the relief from the absence of pain or release from the constraints of being resilient. For several participants acceptance of palliative care as pain and symptom management also helped them to feel better about end of life issues and what lay ahead. In particular, there was a confidence that their final days would be well managed.

P: How I feel here [in SPC]? It changed, it's a big change. It's very, very good here. And I am more relaxed because I know, when I really, moment come, they here with me, and could give me help. And doctors treat me very nicely, and staff treat me very nicely. I cannot imagine even what I would be done without them if I'd been home. I tell you truth. That's you know, it's a very big help.

(White Australian-Hungarian, female, 81-90, lung cancer)

Several participants recognised that a stage had been reached whereby it was clear to them that further life-prolonging treatment would not just be futile, but toxic. In contrast, palliative care's emphasis on quality of life *attracted* these patients and provided a relief from the constraints of the ethic of resilience. For a few participants the move to a specialist palliative care hospital at the end of life provided more than simply relief, it provided a renewal of their spirits, their humanity and even restored

their vitality for life. The following participant, who had previously described how desperate she had felt during her curative treatments, explained the effect of moving to the specialist palliative care hospital for her,

P: So basically now I'm as happy as Larry and I can't believe I'm not only alive, but the pain is under control. . . And the fact that I can maintain some dignity and actually do certain things. (White Australian, female, 51-60, cervical cancer)

She went on to say:

P: And now, since being in here, this is the first time ever that I've actually felt human. I mean I can't actually remember a time before now where I've actually felt half human. I really can't! Since stopping the treatment, . . So, no this is the best I've been the entire time I've had cancer.

Accepting the transition to specialist palliative care therefore allowed several participants to not just experience a void of feeling (cf Kubler-Ross), but was also associated with reclaiming their dignity. More than this, for many, the move was found to provide the opportunity to reconnect with humanity that they felt had been lost in a futile pursuit of resilience during their life-prolonging treatments. However, acceptance

has been described as a ‘morality of dying’ that helps to limit decision-making at the end of life and is part of producing a relational framework of a good death (Broom, Kirby, Good et al., 2012: 232). While moralities often restrict or close down possibilities (cf Frank, 2010), we can also argue that it was the embodied and relational experiences of acceptance that facilitated an opening-up of opportunities and enabled several participants to resist normative experiences of resilience, which many had come to find to be self-defeating. This does not mean that acceptance has wholly escaped its restrictive moral genealogy (cf Broom, 2012; Zimmermann, 2012), but that by locating it within the embodied and relational experiences of the participants it is possible to recognise the important role it played for some in making the move to palliative care at the end of life ‘better’, even if it limited the time left to live.

Discussion

This paper, drawing on interviews with inpatients at a specialist palliative care hospital, has focused on mapping patient experiences of the transition to palliative care to explore their pathways and their embodied and relational experiences during this complex transition. The interviews provided significant insight into conflicting expectations, lived experiences, and the normativities that can problematise transitions, which had been under-explored previously. Experiences of palliative care at the end of life, we argue, are imbued with embodied and relational aspects of dying. In particular, the

interplay of two ethics of care (resilience and acceptance) affected and shaped participant's move to palliative care at the end of life, often opening-up ways to own and re-humanise their care.

A core theme within the participants' accounts was that, despite attempts by healthcare professionals to smooth the transition (cf Gardiner et al., 2011; Larkin et al., 2007b), participants still found that the transition provoked fears and anxieties about what they were leaving behind and what the future held. Those participants who were not familiar with what SPC might entail described how its introduction pushed them to re-engage a curative-hope ethos in their healthcare. Nonetheless, exposure to SPC for them and for many of those who experienced a more gradual introduction to SPC, was found to bring some benefits, such as pain relief, as well as the experience of a different ethic of healthcare. In particular, an ethic of acceptance was (often, but not always) found to problematise previous lived experiences of resilience and provided ways through which some participants came to recognise themselves as approaching the end of life.

A significant contribution that this analysis highlighted was recognising how 'bodies talked' (Harrington, 2008), and how participants placed their experiences within relational networks involving carers, family members and healthcare professionals. Through focusing on these subjective concerns of participants, we were able to

illuminate the ways in which they sought to open-up normative and discursive frameworks available to them and (at times) use them to find relief from those that they had come to feel were toxic for them and their carers/family members. However, these embodied and relational experiences were also the way through which many participants came to an awareness of what was not possible.

In this way we were able to explore a somewhat contradictory dynamic emerged whereby participants talked about prompting change (indicating a capacity as agent) while also yielding to both disease progression and the normative force of resilience and/or acceptance. That is, participants were able to understand their situation both as one where they were an autonomous subject with responsibility for phasing in pain management and managing the end of life process (cf Clark and Seymour, 1999; Lawton, 2000; McNamara, 2004; Seale, 1998), and one where their situation, framed either within norms of remaining resilient or accepting dying, was one that they had limited control over. Moreover, what was particularly interesting was that this was not in itself antithetical to ideas of dying well. Indeed, through engaging the embodied and relational context in which they came to specialist palliative care at the end of life (i.e. pain and symptom management) many participants were able to start re-humanising their medicalised experiences of living-well until death in order to address quality of life issues, along with their existential and social concerns associated with dying.

The problem of transitioning to palliative care therefore cannot be understood solely through allusions to the normative and discursive multiplicity that the participants often found themselves restricted by (McNamara et al., 1994; Zimmerman, 2007). Neither does a focus on the positive attributes of a successful transition (cf Larkin et al., 2007 b) tell us about the lived experiences of how people moved from one healthcare speciality to another. What was needed and what this analysis was able to provide, was an exploration of how participants subjectively localised these strictures, along with their iatrogenic and emotionally negative experiences, to understand what was possible for their self. What emerged was an experience of the transition that fluctuated between forms of resilience and possibilities of acceptance to form an ethic of care with a dynamic, occasionally vibrant, yet increasingly limited actor.

Extending the reach and availability of palliative care services has been the focus within clinical contexts over the last few decades. With its proliferation and now widespread acceptance, the connections and disconnections between palliative and pre-palliative medicine are becoming increasingly evident and sites of difficulty (as well as success). Sociologists have had a long-standing interest in the role of the embodied subjectivities and the consequences for healthcare (e.g. Broom, 2009; Frank, 1995; Novas and Rose, 2000). We have found that recognising the subjectivised dynamics within this crucial

moment in the life course helps to better capture the coexistence and intertwinements of different 'ethics of care'. Therefore the transition to palliative care represents an important site of tension between the limits of the body, medicine, and the desires of patients, families and health professionals.

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