

**Title:** Locating care at the end of life: Burden, vulnerability, and the practical accomplishment of dying

### **Abstract**

Home is frequently idealised to be the preferred location for end-of-life care, while inpatient hospital care is viewed with suspicion and fear. Yet many people with a terminal illness spend their final days in some form of medicalised institutional setting, such as a specialist palliative care inpatient unit. Drawing on semi-structured interviews with inpatients at a specialist palliative care unit, we focus on their difficulties of finding a better place of care at the end of life. We found that participants came to conceptualise home through a sense of bodily vulnerabilities and that they frequently understood institutional care to be more about protecting their family from the social, emotional and relational burdens of dying. For a significant number of participants the experience of dying came to be understood through what could be practically accomplished in different locales. The different locales were therefore framed around providing the best care for the patient *and* their family.

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## Introduction

Healthcare provision in Europe, the US and Australia has recently seen an emphasis on providing people with the ‘choice’ of locating where they want to die, frequently with an emphasis on facilitating home deaths (Bell et al. 2010; Clark 2002; McNamara and Rosenwax 2007). While preference and choice may be discursively centre stage from a service provider perspective in considerations of care and dying, the reality is that decisions on the location of care are frequently multi-factorial (Broom and Kirby, 2013; Broom et al., 2014), limited by financial and logistical resources (AIHW 2013; Mitchell 2011; PCA 2010; Whitaker 2010); influenced by a range of stakeholders (Broom and Cavenagh, 2011; Broom et al., 2012; 2013), and prone to change over the course of the illness (Bell et al 2010; Gott et al. 2004; MacArtney et al., 2015). While most people with a life-limiting diagnosis may initially have a preference to die at home, a significant proportion will die elsewhere (Bell et al. 2010; McNamara and Rosenwax 2007; Jeurkar et al. 2012). Concurrent to the increased focus on the home as a place for dying, there have been attempts to challenge the historically negative depiction of ‘hospital deaths’ (e.g. Field 1989; Glaser and Strauss 1968; Illich 1976). That is, efforts have been made to promote the growing organisational capacity and proficiency of hospice and palliative care in the institutional setting (Clark and Seymour 1999; Connor 2009; PCA 2005). Nonetheless, the question of place is more than a question of clinical need, and the places in which people are cared for pose wider questions around the meaning of dying, the role of the institution, the costs of institutionalised deaths, and the burden/responsibilities of ‘family’ in the dying process (Clark and Seymour 1999; Lawton 2000; Seale 1989). In this article, we focus on how experiences of dying within an institutional setting affect the way in which inpatients understand the places in which they might die.

## Background

### *Producing 'better' spaces for the dying*

Inpatient hospice provide specialist palliative care has been an important location in the development of many of the advances in caring for the dying (Clark and Seymour 1999; Connor 2009; Lawton 2000). The general aim of palliative care has been to improve the quality of life for patients who are living with a life-threatening illness as well as their families, by preventing or providing relief from pain and symptoms (WHO 2002). In practice this can mean that palliative care can be provided in a variety of locations (e.g. home, hospital, residential/nursing homes, hospices), by a number of clinical specialists (e.g. GPs, oncologists, community or district nurses, palliative care specialists) (AIHW 2013; PCA 2005). In particular, recent developments have looked to address previous critiques that dying in institutions like hospitals or hospices routinises care (e.g. James and Field 1992); sequesters dying into institutionalised spaces (Lawton 2000; Mellor and Shilling 1993); or, that palliative care excludes the social and existential aspects of dying in preference for a medicalised rationality (e.g. Field 1989; Glaser and Strauss 1965; Illich 1976). While these critiques point to significant forms of discontent with the management of suffering and dying in institutionalised settings, more recent work has focused on how understandings of dying are experienced in-relation-with the medical experiences of care and dying (McNamara 2004) and draw out the compromises related to the benefits some patients find in contemporary palliative care provision (Broom and Cavenagh, 2011; Broom, Kirby, and Good 2012; Clark and Seymour 1999; Gott et al. 2004; MacArtney et al., 2015; Seale 1989). That is, in order to better understand how palliative care inpatients experience dying we must explore the

“relations of care” (Sayer 2011: 83) in different locales and consider how these compel or attract inpatients to favour dying within an inpatient palliative care setting (Bell et al. 2010).

*The relations of care in contemporary locales of dying*

Understandings of care are often affected by the different locales in which such care is experienced and this is no less true for those who are dying (Broom and Cavenagh, 2011; Lawton 2000; Whitaker 2010). Home, however conceived, is frequently associated with feelings of safety, security and familiarity (Hockey 1990; Moore et al. 2013). Hence the provision of palliative care in the home has sought to facilitate and extend opportunities for dying in the home for many with a terminal illness (AIHW 2013; PCA 2005). However, the provision of palliative care in the community is not always enough to ensure dying takes place in the home. As the dying body disintegrates, people find they are increasingly likely to be located in institutional spaces of care that are both strategically resourced and clinically placed to better manage their care needs (Whitaker 2010). This is because inpatient hospices have sought to provide a manageable space for the dying that espouses a holistic approach, which is focused on patients’ social and existential deaths while also managing pain and symptoms (Connor 2009; Clark and Seymour 1999; PCA 2005).

In practice, inpatient hospices have been found to provide a family friendly, if not authentically home-like, environment where the emphasis is on “cheer and life” (Broom and Cavenagh 2011: 109; Moore et al. 2013). At the same time these spaces also present an opening up of “the potential for the performativity of a good death” (Broom and Cavenagh 2011: 109). That is, there is discordance between the improved enactments of dying and many of the lived realities. For example, while dying with cancer is no longer treated as a taboo, other aspects, such as the messy disintegration of a dying body, can remain

marginalised and silenced (Lawton 2000; Whitaker 2010). In sum, the provision of palliative care in the home and the promotion of the “home-from-home” environment in the inpatient hospice (Moore et al. 2013: 155) have blurred many of the boundaries between the two (Seale 1991). One consequence of the intense deconstruction of the dying process has therefore been to weaken the claim of any particular location to provide a ‘good death’. As a result, a key question addressed in this paper is, how do participants’ reflections on their different experiences of care in the home and inpatient palliative hospital affect their understandings of where they might want to die?

## **Method**

### *Locating the study in an organisational context*

Healthcare services and funding in Australia are provided through a mixed public-private model. Although most core medical services are available through a national health insurance scheme called Medicare, approximately 45% of Australians hold some form of private insurance (Mitchell 2011). Access to healthcare is ordinarily gained via the primary care system with palliative care in Australia being assessed and provided on the basis of need, rather than prognosis. Each state’s palliative care system is structured differently, reflecting the contrasting population sizes and density in different locales (Mitchell 2011; PCA 2010). In particular, within urban areas (such as the major metropolitan centre that this study drew its sample from) the mainstay of specialist palliative services are provided by palliative hospitals,<sup>1</sup> which are therefore the locus for both community and inpatient palliative services (Mitchell 2011). Under this system a patient with low palliative care needs would receive their care at home, supported by their GP and community palliative care services. However, when a patient’s needs become complex or clinically urgent the location of care shifts to a specialist palliative care inpatient unit i.e. there is little scope for the *intense* provision (via

publically or privately funded insurance) of social, nursing or medical aspects of palliative care in the home. Set in this context one of the overall aims of the main study was to provide key insights into people's experiences of home versus hospital care at the end of life.

Therefore, in order to access those with more intense palliative care needs, the study was conducted within a specialist palliative care service that has an inpatient palliative care unit as part of a sub-acute care hospital, along with a specialist community palliative care service i.e. it was typical of many urban palliative care arrangements in Australia. Admissions to the inpatient unit came from the community palliative care service (about two-thirds) and other tertiary referral hospitals (one-third) in the area. Most of the patients have a diagnosis of cancer (approx. 90%), with a minority of patients having a non-malignant diagnosis (cardiac, lung, renal, liver disease and neurodegenerative disorders). The reasons for admission are for symptom control, end-of-life care and respite. The unit has approximately 700 admissions per year, with an average (mean) stay of 14 days, and a death rate of approximately 60%, which was in line with the state (56.1%) and national (51.2%) averages (AIHW 2013).

### *Recruitment*

The lead author's university human research ethics committee and the hospital ethics committee granted ethics approval.<sup>2</sup> A purposive recruitment strategy was used to identify participants who were inpatients on the specialist palliative care unit who had ceased pursuing life-prolonging treatments, were 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. The treating clinician would make the initial approach by explaining the study to the potential participant, providing the patient information form, and asking if the patient might be interested in taking

part. The researcher would then be provided with the details of those participants who agreed to have their details passed on, so that an interview could be arranged if the participant was still interested in involvement. Before asking the participant to sign a consent form the researcher ensured that all of the participant's questions had been answered and that the participant understood the nature of the research.

A total of 44 inpatients were approached to take part in the study and 40 interviews were completed. The sample reflected patient populations found in specialist palliative care in Australia (AIHW 2013). As such, 86 percent of participants were diagnosed with advanced cancer and 54 percent of participants were female. Of those participants interviewed for this study, five participants died within two weeks of being interviewed, seven within a month, seven within two months, two within three months, and eight within six months. Of these participants, 85 percent died as an inpatient on the specialist palliative care unit, 7.5 percent died in another hospital setting, and the remaining 7.5 percent died at home.

The interviews were completed by the lead author and lasted between approximately 15 minutes to one and a half hours; all interviews were digitally audio recorded and fully transcribed. The interviewer was also given opportunities to debrief and reflect with the co-authors and research site counsellor throughout the research. The interviews were semi-structured and sought to cover, when appropriate, four key areas of the patients' experiences of inpatient specialist palliative care, including: reflections on their illness and time before admission; how they came to be an palliative care inpatient; in which location(s) they preferred to be cared for 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 2005). This meant that

the interviewer recognised the polyphonic character of participant accounts and sought to explore *with* the participant how the discourses that emerged in the interview might be affecting their experiences (cf Tanggaard 2009).

### *Analysis*

The methodology for this analysis sits within the interpretive traditions in sociology (Silverman 2011). As part of the dialogical approach of interviewing, 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 participants’ understandings. This approach followed Frank’s distinction between ‘thinking with’ and ‘thinking about’ narratives (Frank 1995: 23). In practice, the approach to 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 participants’ experiences was not subsumed within analytical or writing concerns by maintaining the centrality of the data in any analytical discussion. In particular, it was striking to the authors how participants’ reflections upon their admission to inpatient palliative care were affirming and even upbeat about their location of care, particularly given preconceived notions that ‘home’ should be preferred. The transcripts were therefore initially interrogated for answers to why this might be so. 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 (including location preferences for dying and effects of place on experiences of (palliative) care) to explore possible conceptual tools that would help to elucidate and make sense of the issues raised in the data.

## **Results**

In the interviews we explored whether the participants had considered where they would like to die and, if so, what underpinned their positions on this issue. We did not seek to focus on accounts of ‘care at home’ or seek to provide a comparative analysis of such experiences with those of inpatient care. Instead, we sought to explore how concepts of ‘home’, ‘hospital’ and/or ‘hospice’ were manifest within the inpatient experience. In doing so we acknowledge that these are a select group of participants given they were, at the time, palliative care inpatients, many of whom were nearing their last weeks of life. As such, they might be said to have had atypical health, emotional and relational considerations shaping their reflections. However, as the location of dying affects that process, it is important to explore their experiences of place and meanings therein. We therefore focused on how they had come to reside in the location(s) in which they were dying, where they might die, and if they had discussed their care and dying with partners, friends or family. The emphasis was on exploring how different relations of care had influenced the participants’ coming to a specialist inpatient palliative care unit (bearing in mind some decisions are multi-stakeholder in character and are a result of resourcing issues, as much as patient preferences) and exploring their (ethical) evaluations of these relations in their experiences of care at the end of life.

*Home is where the complexity is*

The starting point for the majority of participants were reflections on their home life, which reflected an initial desire to be cared for and die at home, as has been found in other studies (Bell et al. 2010; McNamara and Rosenwax 2007). The reasons given by the participants were frequently related to the familial and emotional connections participants had with home: as one participant said, “Yeah of course I’d rather be at home, instantly. Still very much in love with my wife, so that’s good enough reason to want to be home”. The desire to return home was also shared by the participants’ loved ones, as another participant explained when she was asked if they would rather die as an inpatient in specialist palliative care,

P: No, I’d rather be at home. I’d rather go home. I said to my husband “I want to get home, I want” - I know it’s going to sound silly, but we’ve been married over forty odd years and I miss him being with me in bed. I know it sounds silly, and I just miss him . . . He said “I want you to come home,” I said “so do I.”

This participant went on to say,

P: So I think the aim is to get home, and I think probably that’s most people’s aim actually to go home. Because I think most people want to be home, because its familiar and you’ve got your own bed and you’ve got your own things around you and you can eat what you want, you don’t have to have the diet, you can have what you want, which is probably better for you in a way. (Female, 61-70, colorectal cancer, white-Australian)

However, increasingly in the post war years, as the home has become normalised as a space for the living it has consequently become a less appropriate space for dying (Hockey 1990). The division in locales between the home and the hospital, of wellness and sickness respectively, came to separate what the participant believed to be possible for her. While she wished to be at home, she said she also recognised that she needed to be an inpatient to achieve the pain control she needed, but her admission was conditional “just so long as I can go home”.

Several participants’ experiences reflected this dilemma of wanting to be at home, but realising that at home it was not possible to receive the pain and symptom control that they needed. As this participant explained,

P: Well all the conveniences are here [on the specialist palliative care inpatient unit]. And the people are here if you want to speak to one of them, well there’s someone here to ask. But being at home you’d have to wait until they came I don’t think it’s anywhere near as convenient . . . Whereas if they’re calling at your house, well, they have a certain time and that’s that. So you’re, you’re controlled more; you can control more [than] at home [when] you are here. (Female, 81-90, breast cancer, white-Australian)

For numerous participants ‘home’ was viewed through a fragile and wounded body (cf Frank 1995), which transformed a place of comfort and familiarity into a space where they felt vulnerable and exposed. For example, the following participant described how, while he was aware that most people might want to be at home and that his wife was keen for him to return, home was now a place he feared,

P: I need a lot of looking after at the minute . . . so for me to go home now I'd be scared of something going wrong. So far better to be here, because I just need too much care to be home, I struggle to do anything, it's two or three people, because I'm not a little guy.

(Male, 61-70, MND, white-Australian)

As this participant alluded to, an important consideration for almost all those participants who considered dying at home was the burden this would have on their partner, carers, family, and friends. As well as recognising that the dying body might need more assistance than the community healthcare services could provide, participants were also well aware that their carers and family had other obligations, including work or other people to care for, such as children. Indeed, as another participant made clear, "So that's my major concern, is not for myself, but the extra burden [returning home is] placing on [his wife]". Another participant explained when considering where he might die, "I would be thinking more what's best for the kids, not what's best for me." Therefore, while ideas of being a burden were occasionally related to limitations in community palliative services, it is important to note that for many participants ideas of burden were actually framed through a lens of protecting carers, family and friends from having to care for them and having to cope with their dying. As one participant said, by not dying at home it allowed his friends to "Just remember me as I was."

A few participants sought to explain what it was they were hoping to protect family and carers from. The following participant explained that she was happy to be an inpatient on the specialist palliative care unit as they could help manage her breathing better than when at home. But she went on to reflect on recent deaths of a couple of friends and the impact their dying at home had on their respective families,

P: And it's been hell for them, absolute hell. And I think it probably damages the family more, because the person who dies might get that small comfort. . . . [But] the wreck is left behind, and I don't think that's fair on your family. And I also think your own self-confidence and dignity, because you asked, I think if you're in a facility where they are geared for every eventuality, no matter how horrendous that may be, they can make the best of it. And I think that's good for the person who's dying as well as for the family because they know that everything that can be done is being done. (Female, 61-70, breast cancer, white-Australian)

It would appear that if homes are places of living (Hockey 1990) then, for numerous participants with high palliative care needs, dying at home significantly detracts or potentially even “wrecks” that space for those that remain. That is, being cared for at home at the end of life brought to the fore difficulties in accessing necessary pain and symptom care; problems of how physical care will be administered (and by whom); awareness of the logistics of family and carers managing their multiple caring roles (for the participant, other parent, and/or children) along with employment responsibilities; and, recognition of the negative emotional consequences of having a loved one die in the home. Furthermore, in participants' accounts we can increasingly hear not only the problematisation of a home death, but also the attraction of dying in a locale where “everything that can be done is being done”. While this statement is usually associated with prolonging life (Reyniers et al. 2014), here and with other participants, the sentiment was associated with a place where they could receive better care and be made comfortable as the end of life approached. As the participant explained this benefitted her, as she could expect to die in dignity, and benefitted her family, who were relieved not only of the burden of care but could also be reassured that by supporting the

participant in the hospital they were helping her attain a better death than was available at home.

*When a hospital is not a hospital*

The majority of the participants saw inpatient specialist palliative care as not only a refuge from the complexities of home, but a place that provided an attractive level of quality care. Of particular interest is that the inpatient specialist palliative care unit was viewed almost unanimously by the participants as a hospital (rather than being described within the interviews as a hospice), yet this frequently came with the caveat that the participants were experiencing subtle differences in the quality of the care provided. As several participants noted, they were “pleasantly surprised” with the difference in quality of care and the atmosphere on the unit vis-à-vis other hospitals – of various types – that they had previously encountered. As one participant said, “I was relieved to get out of the [cardiology ward at the acute hospital], because it’s a hospital. Although this is a hospital, it’s not a militarised as some.” Similarly, almost all participants had previous experiences of stays in acute hospitals to contrast their inpatient specialist palliative care experiences to. As this participant said:

P: I think they [the inpatient specialist palliative care unit] make it more personalised in their asking of questions of you, and listening to you. Whereas the [oncology department at the acute hospital], where I’ve been numerous times, it’s more a, just a sausage machine. And that’s a very big difference between the atmosphere here [and the acute hospital]. (Male, 71-80, prostate cancer, white-Australian)

A small number of participants spoke of how the emphasis on the quality of interaction was linked to the unit's capacity to provide them with the death that they wanted. As the following participant said,

P: So it's a very big change to what had gone on before [being at a specialist palliative care inpatient unit, rather than acute hospital]. So as far as here, no-one's interested in actually in what's wrong with my heart because what's it matter? All you've got to do is treat symptoms, we don't want to look at the cause, or fix the cause or do something better with the cause because there's no point in lasting another month or another week or another few days, sooner or later MND's going to take me out.

(Male, 61-70, MND, white-Australian)

The move to inpatient specialist palliative care therefore appeared to provide a markedly different hospital experience in three broad areas: the quality of the care provided; the technical competence of the clinical staff with dealing with pain and symptoms of a dying person; and, the capacity to provide an environment where the person is able to die well and as they wished. As the following participant explains, for her moving to inpatient specialist palliative care "was like a cloud lifting really, because everything here worked, it works brilliantly. . . to the point of view that if I'm dying, I should be allowed to die with dignity".

This feeling that inpatient specialist palliative care was a better type of hospital more suited to dying with dignity did not, however, always extend to participants changing their preference as to where they would like to get their care. As the following participant explained, the benefits of home were associated with remaining resilient and the care received in the inpatient specialist palliative care unit did not always correlate with this: "I'm

trying to fight the disease [MND] as best as I can, and that's why I express the feeling that perhaps I should be released and be able to go home." Another participant explained how coming to the unit had changed the burdens he felt were on his family and carers, as "people have got to come in and visit you and it puts them out; like no-one says it's a problem. . . ." As we explore in detail in the following section, the move to inpatient specialist palliative care was not considered to be wholly positive, rather it provided a different balance of care, which some participants (but not all) found beneficial as they approached the last weeks of life.

In sum, the desire to move away from the home was, for several participants, premised on feelings around protecting carers, family and friends from the physical and emotional burdens of dying. It was therefore understandable that part of the attraction of being an inpatient on the specialist palliative care unit was that it provided a locale where there was a clustering of expertise to care for people at the end of life and better manage dying. This extended to both ensuring that the pain, symptoms and terminal care are competently managed, as well as providing an environment where the participant was able to contemplate and engage the social and existential aspects of dying with 'dignity'. In this context then, inpatient specialist palliative care appeared to have provided many participants with the answer to a problem. In the following section, we return to the locale of the home to contrast what sort of solution the specialist palliative care inpatient unit was found to provide.

### *Locating dying as a practical accomplishment of better care*

In this final section we explore how the participants, many of whom continued to express a preference to be cared for and die at home, came to find dying as an inpatient in the specialist palliative care unit as the right place for them. To do this we unpack the judgements



associated with spaces of care and how these were connected with different locales of dying. What we start to find is that where people are cared for, and how this is related to where they die, is more complex than fulfilling a preconceived desire to die in a certain place. It involved consideration of numerous factors including those related to the impact of dying on carers, family and friends, as well as the participants' need for prompt pain and symptom management. What we are interested in exploring here are not the outcomes of those deliberations (the home or specialist palliative care inpatient unit), but how the participants came to understand either as a better (or worse) place for their end of life care. As one participant explained,

P: There's a huge appeal to being . . . in your own home environment. But *realistically* speaking, the best place for you when you're unwell, really unwell, is hospital. And so I think there's a place for both, but I'd much prefer to be out of here, than in a hospital room. (Emphasis added; male, 71-80, prostate cancer, white-Australian)

The idea that being cared for as an inpatient on the specialist palliative care unit was the best compromise option was also summed up by a participant who, when asked whether they would like to change anything about being in on the unit said, "Not unless you could put [inpatient specialist palliative care] in our home, have full staff in our home. No, not really..." While the starting point for many participants was the desire to be cared for at home, as they got closer to the end of life they became aware of a diverse array of factors that also needed to be taken into consideration. However, instead of disgruntlement, anger or critique of not being able to get the level of care in the home that they needed, the participants' framed their situation as one where they sought the best of what was possible.

The participants' understandings of where they were able to get their care and how it might affect where they would die extended beyond ensuring timely pain and symptom management to the impact dying had on carers, family and friends. The following participant explained that his wife, who would have to care for him if he returned home,

P: Well she's got a few health issues and I don't want to put too much on her, you know? If it's, if everything was manageable, yeah I'd go home, yeah. But if it's not *practical* I'll have to stay here. (Emphasis added; male, 61-70, pancreatic cancer, white-Australian)

The constraints of what was practical also extended to those who lived on their own when they considered where they would spend the last days and weeks of life. As this participant said about moving out of her home,

P: I don't want to, but you've got to be *realistic*, when you're on your own . . . You've got to be *realistic* yeah, because I don't want to be dependent on my family. If I'm independent it's a big thing really isn't it, your independence. (Emphasis added; female, 71-80, post-encephalitis, white-Australian)

It is therefore important to note that the move out of the home could also be seen as a way of extending that person's independence – in this case from their family. As such, what is realistic does not necessarily need to be viewed as limiting or restraining. Another participant explained, "If I need palliative care, I'll come in here. If it's not suitable to be managed at home, if that's not working, wife's not coping or the system's not working that well for me,

I'll come here." For this participant the idea that the move out of the home and away from the "system" of care provided there holds the potential for him and his wife to get more out of his last days of life. Home is judged not to be a "suitable" place to be cared for, as it is not able to provide the palliative care that he will need to sustain a good quality of life. Like a number of participants, as he neared the end of life he recognised that his needs were changing and, with this, that it would help him attain a better level of care if he moved out of the home. As this participant said,

P: Yes. I'd be happy if I could have [my care] at home, but it's too much for, to have this amount of care at home. . . So yes, here is where I've got to be. It's just a *progression* from where we were. I was at hospital treating me for my cancer and everything, but now here's the terminal hospital care I guess. (Emphasis added; female, 61-70, colorectal cancer, white-Australian)

Most participants recognised that the best place to be cared for changed, as their physical, emotional and relational needs changed. The participants described their coming to be cared for as an inpatient on the specialist palliative care unit in terms of what was "realistic", "practical", "suitable" and as part of the "progression" of dying, reflecting the interplay of relations, discussions, decisions, and (enforced) choices of their illness journey. As such, managing the complexity of what was involved when dying was experienced as a practical accomplishment, grounded in the realities of their situation and not beholden to preconceived idealised notions of where would be a good place to die.

## Discussion

In this paper we have drawn on semi-structured interviews with inpatients at a specialist palliative care unit in the last few weeks of their lives. We have explored how patients with acute palliative care needs experienced different locales of care and how this impacted their understanding of dying. While previous research has sought to emphasise the positive benefits of a home death for those who are dying and their family (Catalán-Fernández et al. 1991), what is notable from these findings is that those who are dying provide a similar emphasis upon providing the carers, family and friends with a positive experience, but this led them to question the practicalities of a home death. While further research is needed to explore dying in the home and how that affects understandings of dying, in this study, not only was the idea of a positive experience displaced from the home environment but the negative aspects of dying at home – for themselves and others – were also a focus of participants accounts. In contrast, exposure to specialist palliative care led many participants to find reasons why it was a *better* place for their end of life. So while home remained the ideal location, being in an inpatient provided more *control* over their care than could be attained at home, as well as *protecting* carers, family and friends from the burdens of their dying (cf Broom and Kirby, 2013). Therefore, for the participants in this study, judgements were made on the basis of which locale best dealt with the multiple physical, emotional and social practicalities of being cared for when dying.

This is an important finding as it tempers generalisations based on understandings drawn solely from preconceived wishes about where a person might wish to die, particularly if these preferences are simplified within discourses of choice. Analysed within such a framework it might be argued that the study's findings are limited, given that the participants were largely urgent admissions to an inpatient hospital and so were unable to express much of a 'choice'

in deciding where their care would be located. However, while listening to the participant's accounts of their somewhat 'unfree choices' might be an ethical worthwhile process in itself (cf Frank 1995), we argue that an a priori framing of the accounts within a discourse of choice will miss, or at least negate, the ways that other narratives affect people's experiences of how they experience, understand and evaluate the locale of their care.

We can further demonstrate this if by considering the participants' warm, if restrained, experiences of inpatient care, which contrast with concerns within the literature around the sequestering the body, and the medicalisation and bureaucratisation of dying (e.g. Field 1989; Glaser and Strauss 1965; James and Field 1992; Lawton 2000). These critiques of the instrumental forces structuring experiences in inpatient institutions were not able to fully account for the participants' feelings of vulnerability and burden. This is because participant's emotive accounts contained not just forms of affect, but also evaluative judgements (i.e. normative) of what people value and what they consider to affect their well-being (Sayer 2005). That is, it is through consideration of the emotional reasoning (Sayer 2005; 2011) of participants it was possible to contextualise what at first might appear to be a (unexpected) 'pro inpatient specialist palliative care' stance. By giving proper regard to the emotional and physical problems that inpatient specialist palliative care was found to help resolve, we were able to show how the participants' concerns about the vulnerability of their dying bodies combined with the problem of over-burdening carers, family and friends so that 'home' became imbued with negative *normative* judgements, even if their (positive) *feelings* for home remained the same. This distinction allows us to recognise how experiences of burden (understood as a manifestation of a wider moral injustice i.e. social and personal *obligation*) become weakened in favour of the emotional aspects of participants' everyday

lived experiences in their “relations of care” (Sayer 2011: 83). The best care was then understood as something that could be practically achieved as circumstances changed.

The language of burden has not just been used to describe the relationship of the ‘patient’ to their ‘carer’ (or vice versa), but also to describe patients’ (and their carers’) relationship to the state’s healthcare provision (cf McNamara and Rosenwax 2007); a system that in many countries is already underfunded and that has projected increasing costs due to aging populations (NIA 2011). While palliative care can be successfully provided in the home (PCA 2005), this study highlights that the successful management of pain and symptoms at the end of life were not the only concerns of many participants in this study. Wider social and relational questions about how the place of care would affect carers, family and friends were as, if not more, important. Therefore, our findings suggest that if healthcare systems were able to better manage patients’ vulnerabilities in the home, then there may be an increased congruence in the desire of patients and the aim of healthcare planning for people to die at home (cf Bell et al. 2010; Whitaker 2010).

Framing the understandings of dying as a practical accomplishment of receiving ‘better’ care – for the participant *and* their family – gives some indication of how far attitudes to dying have come in OECD many countries. That is, the public-private questions of sequestered dying (Mellor and Shilling 1993) have somewhat receded as palliative care continues to transgress and breakdown disciplinary, medicalised, and care-based boundaries (e.g. Field 1989; Glaser and Strauss 1965; James and Field 1992; Lawton 2000). Further, while the stigma of dying isolated in a hospital setting remains (Clark 2002), it would appear problems around the medicalisation of death and dying can be negotiated by addressing the social and clinical practicalities feared by those who are dying. Finally, while dying at home is desired

and holds significant rhetorical, emotional and cultural value, it was remarkable how little resistance there was to abandoning this apparently strong desire. That is, the current moral economy of dying would appear not to be one where dying at home is to be achieved at all social and economic costs. Rather, finding the right place to die is something that is to be negotiated, compromised and practically accomplished.

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<sup>1</sup> In the Australian healthcare context, while the label 'hospital' is preferred (and specialist palliative care unit therein) the traditional hospice approach and model drive the broad operational approach.

<sup>2</sup> The national ethics process is governed by the National Health and Medical Research Council's national statement of human research ethics, which sets the standards for appropriate and ethical collection of data, including research within vulnerable populations. The project was developed and conducted in strict accordance with these standards.

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