A post-structural rethinking of the ethics of technology in relation to the provision of palliative home care by district nurses

Abstract

Technology and its interfaces with nursing care, patients and carers, and the home are many and varied. To date, healthcare services research has generally focussed on pragmatic issues such access to and the optimisation of technology, whilst philosophical inquiry has tended to focus on the ethics of how technology makes the home more hospital like. However, the ethical implications of the ways in which technology shapes the subjectivities of patients and carers has not been explored. In order to explore this, post-structural theory, in particular the work of Butler, Foucault and Deleuze, is used to theorise the relationship between subjectivity and materiality as ethically mandated on producing rather than precluding the development of subjectivities in novel ways. This theoretical understanding is then utilised through a process of 'plugged in' as described by Jackson and Massie that aims to link empirical data, research and philosophical inquiry. Through this process it is suggested that power, which the empirical data demonstrates is frequently exercised through medical discourses, restricts patients' and carers' ability to shape the material environment of the home as a place to live and be cared for in palliative stages of illness. Alternative discourses are suggested both from the empirical data as well as other research, which may offer patients and carers the possibility of reclaiming power over the home and their subjectivities. Finally, the dichotomy between the home and hospital,

mediated via technology, is posited as being problematic. It is argued the dichotomy is false and should be moved away from in order to allow an ethical embrace of technology in palliative care.

Introduction

This paper combines post-structural moral philosophy and data from a qualitative study to examine the ethics of how the home, patients, carers, nurses and technology interact in relation to palliative home care. In order to give context to this study it is important to review some of the key concepts that already exist in the literature, namely: palliative care, district nursing care and technology, and the morality of home care. After these three topics are reviewed a brief summary of the way in which the empirical data was produced and analysed is given. Following this, the paper explores the morality of home care using post-structural theory weaving empirical data, theory and research together, concluding with a discussion of how this shifts understandings of technology, materiality and subjectivity in the home. It is not the intention of this article to examine specific types of technology in detail, but instead to develop a broader understanding of the morality of the topic area. But for clarity, technology in this paper can be taken as having a broad

definition as described in Liaschenko's (1994) work which ranges from beds and mattresses to advanced haemodialysis, and whilst this paper does take a post-structuralist approach, in this case technology is not being used in the post-structuralist sense of 'technologies of power' as described by Foucault (1977).

Background literature

Palliative care

Palliative care has been defined by the World Health Organisation as being focussed on achieving "quality of life for patients and their families facing the problems associated with life threatening conditions" (Sépulveda et al. 2002, p. 94). The definition goes on to highlight the need for high quality assessment and treatment of symptoms, as well as ensuring a holistic approach that goes beyond medical treatments encompassing psychological, spiritual and social support. However, the definition makes no comment on where the care occurs and how this may impact on the quality of palliative care. Research consistently highlights that the majority of people want to die at home, yet only a minority achieve this (Holdsworth and Fisher 2010; Arnold et al. 2012) and whilst it was predicted that home deaths would continue to decrease over the coming decades (Gomes and Higginson 2008), more recent evidence suggests that in the UK this downward trend is slowly beginning to reverse (Gomes et al. 2012). This may be due to government policies that have over

recent years consistently drawn up aims and targets to increase home deaths (Department of Health 2008; NHS England 2014). However, focussing on the number of home deaths is only part of the picture. For example, Grande and Ewing (2009) suggest that for bereaved carers it was how patients died rather than the place of death *per se* that mattered, whilst Agar et al (2008) highlight that the place of care during the last stages of an illness is an equally important consideration to the final place of death.

District nursing palliative care and technology

In the UK district nurses are one of the key healthcare professionals who provide palliative home care, a type of care which they have historically placed a high value on providing (Griffiths 1997). The research in the early part of the century also suggests that district nurses play a key role in palliative home care by: performing holistic assessments, providing personal care, emotional care, care co-ordination, and visiting early on in the disease trajectory to build a therapeutic relationship with patients and their carers (Hallett and Pateman 2000; McGarry 2003). However, in more recent years district nursing palliative care is operating against a background of decreasing district nursing numbers yet an increasing workload (QNI 2011). Whilst research has previously documented that district nurses will sometimes subvert the limitations placed on their workloads such as by lighting fires and by offering their personal contact details in case of emergencies (Speed and Luker 2004), it seems that

holistic nursing is becoming increasingly difficult to conduct as much of the personal care (such as washing and dressing) has been transferred to less expensive care assistants (QNI 2011) and more recent research suggests that patients perceive the district nursing role as primarily encompassing medication administration and dressings with uncertainty about their role in psychosocial and personal care (Nagington et al. *In press*). Other literature suggests that home administration of intravenous therapies is now within the remit of some district nursing services (Milligan and Knight 2012; Holmdahl et al. 2014). Therefore, the legitimate tasks that are considered valid in contemporary district nursing are tending towards being increasingly reliant on more advanced forms of technology such as precision manufacturing of dressing products and intravenous medications which are utilised in relation to specific medical conditions. There is then a simultaneous move away from a personalised holistic form of nursing, for example Nilsson et al (2010) suggest that district nursing is beginning to incorporate digital forms of technology to mediate the social relations between district nurses and patients in a more efficient way. It is claimed this approach still offers high quality care, but the drive for efficiency has been questioned and it may even impact negatively on the psychosocial aspects of district nursing care (Nagington et al. 2013). This coupled with Griffith's documentation of a move away from holistic care (Griffiths 1997) towards care that ignores psychological needs (Griffiths et al. 2010) suggests what counts as district nursing in a contemporary context is

becoming tied to medical technology and efficiency for all aspects of care, with face-to-face, hands on holistic care becoming problematic and inefficient.

Morality of home care

The morality of home care and technology is not a new topic, Liaschenko (1994, 1996) explored the way in which home care functions in a US setting by using Foucault's (1973) theory of the medical gaze. Foucault developed the gaze as a way of theorising the power that medical knowledge has to interpellate subjects as patients and how medical discourses go onto organise patients in the most efficient way for the medical practitioners to do the work of diagnosing and treating. Liaschenko extended this idea into home care by theorising the presence of a nursing gaze that comes to shape the home care environment in the most efficient way thus turning homes into hospitals through increased technological advancements where "the agency of the dominant practitioners is preeminent" (Liaschenko 1994, p17) which Liaschenko argues subverts the beneficial nature of the home. Liaschenko bases this argument on technologies that remotely monitor patients' medical condition and draws a parallel with how nurses entering the home is more about extending medical monitoring beyond the hospital rather than offering holistic care. She also alludes to the possibility of other medical technologies such as haemodialysis beginning to enter the home to treat disease, something that has since become increasingly commonplace (Walker et al.

2015). However, in a UK setting timely provision of even more basic technology for patients with palliative care needs such as beds and mattresses is cited as frequently problematic in providing home care (O'Brien and Jack 2009) and hence the problematic subversions of the home that Liaschenko suggests through increased technology and monitoring may in fact remain something which is only available to a privileged few. Further research about this is clearly needed to understand inequity of access to the technology that supports care.

Finally, in contrast to Liaschenko who places a high regard on the home as something that is interrupted and changed by nursing, other authors have viewed the home as a social construct (Gott et al. 2004). This has the implication that there is a fluidity to the material spaces where care occurs, with hospitals becoming homes, or conversely homes becoming hospitals (Collier et al. 2015). In the case of palliative care, using the home as a hospital allows a person to die in their place of choice, but whether the home remains the same place remains questionable.

Summary

The provision of palliative care in the home has been consistently demonstrated to be of particular importance to patients and carers, and there is a clear consensus about the value of district nursing involvement in home palliative care in that without their involvement, fewer people would have a

good death at home. However, research thus far has focussed on the interactions between the patient, carer and nurse, with less attention paid to the way that district nursing interacts with the home. The role that technology plays in directing the morality of such care has been theorised, but not directly in relation to palliative care, and patients' and carers' perspectives have not been incorporated. Hence there is poverty in understanding the morality of the relationships that may be occurring. Importantly, the accounts of home care to date are all constructed around the understanding that there is a one way interaction of either the home affecting care or care affecting the home.

Background to empirical data

In order to give context to this paper it is important to give a brief background to the production and analysis of the empirical data, a more detailed discussion can however be found in Nagington et al (2013; *In press*).

Participant recruitment occurred between September 2010 and October 2011 in five community healthcare trusts (healthcare trusts broadly cover town and city areas, though may at times encompass several smaller towns and villages, or may conversely cover smaller sections of larger cities) and five hospices. Healthcare staff or research nurses approached patients with a palliative diagnosis who were receiving district nursing care, if they agreed to participate their carers were also invited to take part. See box 1 for the full list of inclusion and exclusion criteria.

Data was produced by conducting semi-structured qualitative interviews with twenty six patients and thirteen of their lay carers. Three cases were interviewed twice P6, P7, P12. Interviews occurred in a variety of settings depending on participants' preferences, venues included: participants' homes, University premises, and in private rooms in hospice day care centres. All interviews were audio-recorded, professionally transcribed and then checked for accuracy before being entered into NVivo (a qualitative data management programme). The interview protocol was developed iteratively (Charmaz 2006), a summary of the topics covered across all interviews can be found in box 2. The concept of 'data saturation' was used to establish when data collection should cease (Marshall 1996).

For the purposes of this paper the data are going to be interwoven with post-structural theory in a process that Jackson and Mazzei (2012) have termed, plugging in. In summary, Jackson and Mazzei draw heavily on Deleuze and Guattari (1988) who suggest that all texts can be plugged into different machines, broadly this can be understood as a form of discourse analysis. However, Jackson and Mazzei take the process of discourse analysis further by arguing that the process of plugging-in is not a one off affair, but is instead is a continuous affair with data and theory entering into a dynamic relationship that pushes the boundaries of one another. Hence, the rest of this article

proceeds by presenting theory, then data, and then more theory in a continual fashion to iteratively develop the philosophical discussion.

Post-structural morality

The morality of home care has been discussed in relation to how technology alters the home. However, the alteration of the home relies on the view as expressed in other literature that the home is fixed as a 'natural' place of death and care at the end of life (Bowling 1983; Higginson and Sen-Gupta 2000; Gott et al. 2004; Barclay and Arthur 2008). Such research does not and cannot attempt to theorise a dynamic account of how patients, carers, district nurses, technology, and the home interact; nor does it take account for how the home was already being constructed. Post-structuralism offers such a framework, primarily because it rejects the notion of anything being natural and/or pre-existent. Instead, post-structuralism considers concepts and identities to be linked through constant and shifting performances (Butler 1997a). For example, Butler (1990) views the concept of gender as a performance with subjects constantly having to perform gendered ways of being, such as particular ways of dressing. By identifying (both themselves and by society) with one of the binary gender positions (male or female) the discourses performed become increasingly sedimented as either male or female and hence increasingly become required to be performed in the correct way by either male or female subjects (a binary that is mandated through the

differential performances). Butler's performative theory has been expanded to include a wide range of other social categories such as race and class (Rottenberg 2004; Muñoz 2006), but the role of materiality has generally been sidelined. In order for a discussion of subjectivity and materiality to be undertaken it is important to understand one of post-structuralism's key contributions to philosophy, the understanding of power and knowledge in relation to subjectivity.

Post-structuralism moves away from modernist views of power, which understand it as something that can be possessed by individuals, towards an understanding of power which 'circulates', forming and reforming subjects (Foucault 1980; Butler 1997b; Cheek 2000). To be clear, 'subjects', is not merely another word for individuals. It is instead a concept which encapsulates the discursive position that is carved out that individuals will then go onto occupy but not possess (Butler 1997b); in this case patients', carers' and district nurses' subjectivities form the focus of interest. With regards to how this happens Foucault (1973, 1977) argues that power is neither positive nor negative, instead it is productive producing practices and positions of subjectivity primarily tied with institutions such as hospitals by sanctioning the knowledge that is valid, thereby giving power to knowledge, and knowledge power. Whilst in his later works and lectures Foucault begins to theorise how power permeates society to the smallest details, it is not always clear theoretically how it occurs outside of an institutional setting other than through a rather unspecified and under theorised trickling down effect from institutions

to individual lives (Foucault 1977, 1980). Therefore Foucault's understanding of power whilst usefully refuting the idea that individuals possess power, remains theoretically tied to institutions and only shapes rather than forms the subjects.

Butler takes Foucault's ideas of power and intersects them with psychoanalytical theories (Butler 1997b, 2005). By doing this Butler aims to understand how subjects are not only reformed by, but come into being through power and knowledge. For Butler, unlike Foucault, power forms the initial viability of the subject, without being subjected to power, subjects are unable to enter into the social world and in doing so becoming a viable being (Butler 1997b) and because this subjection pre-exists the subjects existence, subjects are unable to account for how power forms them. In addition, Butler stresses that:

> "[subjects] pursue subordination as the promise of existence… [yet] becoming [a subject] is no simple or continuous affair but an uneasy practice of repetition and its risks, compelled yet incomplete, wavering on the horizon of social being." (Butler 1997b: 30)

It could appear from the above that Butler suggests a deterministic account of subjectivity where there is little to no opportunity to live one's own life, this however is not what Butler is arguing. Instead Butler is trying to demonstrate that one must first become a viable subject who acts in the social world via

extant discourses, which the subject has no control over. Once viability has been achieved one can begin to question and challenge, exceeding but not escaping one's subjectivity in multiple ways through repeating discourses in different or even sometimes erroneous ways, but that performance of something is continually required (Butler 1990, 1993, 1997b). However, it is this very requirement to repeat discourses constantly which suggests that they are in fact unstable and therefore changeable (McNay 1999), despite there always being a primary subjection to power and knowledge. It is the ability for these power and knowledge structures to be reworked that forms the central tenant to post-structural morality and is expressed most clearly in the work of Deleuze and Guattari in their conceptualisation of 'becoming-other' (Deleuze and Guattari 1988). Put simply, becoming-other is a way of conceptualising subjectivity as not only being constantly repeated, but also constantly shifting in order to try and avoid the restricting nature of extant fields of power and knowledge. Becoming-other therefore necessitates the taking on and performance of a constantly changing range of discourses. Such a becoming-other (whether or not that specific wording is used) is argued for across a wide range of post-structural literature, and Butler has argued that by engaging in the processes of breaking down extant fields of power and knowledge lives are made more liveable by virtue of there being more discursive places for subjects to inhabit (Butler 2004).

The above arguments can be synthesised to conclude that discourses which produce a becoming-other can be argued to be moral, whilst those discourses

that preclude a becoming-other can be argued to be immoral. As a tangible example of this, the authors have previously argued when discourses of busyness come to form district nurse subjectivities, patients and carers in turn become docile and are precluded from identifying as being patients with needs that go beyond physical care. Conversely, when friendship came to form district nurse subjectivities patients and carers were able to explore their needs in a more comprehensive way to include psychological and social support. Hence, busyness is representative of a preclusion of becoming-other, whilst friendship is representative of producing a becoming-other (Nagington et al. 2013). A purely discursive and post-structural approach to morality can therefore be productive, but it remains unclear how and if material circumstances come to (re)form subjective experience. Without wanting to be facetious, within post-structural theory one could largely imagine disembodied 'beings' doing the work of power and knowledge and becoming-other. Whilst Butler approaches the material in some of her works (Butler 1997a, 2004) it only tends to be in relation to the fact that bodies can be physically injured, or that bodies are inscribed by discourse of gender to produce set ways of understanding bodily sex in the social world (Butler 1990). There remains no coherent exploration of the ethical interactions between materiality (outside of institutions, such as the home) and subjectivity. The empirical data in this project can help develop an understanding of these links.

Therefore, it can be concluded that the home functioned as a place for a variety of care to take place and our previous papers demonstrate that

patients and carers almost ubiquitously agreed with the literature that district nurses provided care such as dressing changes and medication management (Nagington et al. 2013) [NI paper], but it was this district nursing involvement that maintained the home as a viable place for patients and carers to remain:

> "*P21: Being away [from home] is not a nice experience, certainly not the one that I went through, but being at home is absolutely vital.*
>
> *Interviewer: Yeah. So how important are the district nurses in keeping you at home then?*
>
> *P21: You know, well, they're vital*"

However, for district nursing to carry on, illness had to be of a certain type or severity. For example, several patients described episodes of unexpected illness that meant district nursing care was no longer a viable care option:

> "*P25: Yes. But I mean every time I've been admitted to hospital they couldn't have treated me here because I've been admitted with that many heart attacks that they have to get you away, hadn't they? I was rushed in a few months ago… every year I've been in hospital since my husband died, haven't I, it's been one thing or another.*"

Whilst district nurses often provided the majority of care for patients at home, it was not always district nurses or patients who made decisions about whether care could be managed at home. Instead it was other healthcare professionals with a variety of social identities such as primary care physicians (GPs) and specialist community nurses. Yet the uniting factors was the use of particular forms of medical knowledge about where and when care should be directed:

> *"P19: It was last week that my hand started swelling up, and they'd [district nurses] noticed so they phoned my doctor, doctor came out and said that I needed to go into hospital."*

In such cases, the hospital admission was not read by patients as being due to district nursing. Instead it was read as a medical necessity, best practice, which exceeded district nursing and the home. Such medical discourses become performed by the district nurses by allowing greater privilege over other discourses, such as a desire to remain at home that was expressed by some patients and carers:

> *"P19: I'd rather spend my time at home with the family than in hospital with a load of strangers."*

Even though in many cases it wasn't the district nurses diagnosing and directing care, sudden or acute illnesses often proved outside of the remit of being manageable at home:

> *"P7: when the time comes… I'd be quite happy to have*
>
> *the district nurses… it depends how severe my illness is*
>
> *at the end… if I need a load of lifting and this, that and*
>
> *the other, I need a lot of support in doing, and it's*
>
> *affecting her [my wife], then I would rather be in*
>
> *hospital."*

In such statements no thought was given by patients or carers about whether district nursing services could alter or provide extra care to manage 'severe' illness at home. Instead, district nursing started to become unviable when faced with severe illness but for reasons that were unclear and unknowable. In addition, no clear guidelines were even given regarding what care could be managed at home:

> *"P17: I think you've to sort of recognise a point where*
>
> *you can be cared at home and when you can't be, you*
>
> *know. I think that's, I mean obviously I think you… if*
>
> *you're poorly there is a line where I think, you know, you*
>
> *need to be in hospital and then a line where you can*
>
> *think right, no, I can probably come… home."*

The line that P17 talks about is not a clearly defined line, but its presence permeates the home environments by serving to draw boundaries of what can and can't occur within the home. An emphasis is also placed on the patient to recognise and accept this line rather than reform and develop such a line in

conjunction with district nurses. However, with the clear lack of knowledge it is unclear how patients possess power to instigate any reformations around the boundaries of home care.

The home however, was not only a site of care but was a site of creating identity for patients and carers facilitating the continued performance of patients' and carers' subjectivities:

> "C15: it was a lot of talk at the hospital…in fact they suggested that he [P15] might go into a nursing home. And we said no, because it would have finished him off"

Without this site of identity it was felt that patients would literally be finished off; the boundaries between social body and physical bodies in patients' and carers' representations were far from distinct and the ways therefore in which the home permeated subjectivity begin to be revealed. The above quotes suggest that the material environment also performs some form of inscribing of subjectivities with discourse, and hence it becomes important to consider the morality of the material environment and how space gains the power to perform the work of shaping subjectivities. As mentioned earlier, several authors (Bowling 1983; Higginson and Sen-Gupta 2000; Gott et al. 2004; Barclay and Arthur 2008) have suggested that the home is a natural place of death, and if such suggestions are read in line with the work of Liaschenko

(1994), one could conclude the home gains its power to inscribe subjectivities through being such a natural place which can be (negatively) impinged upon by the nursing gaze and technology. However, as discussed post-structuralism rejects the notion of any concepts being natural and hence having the power to construct. Instead concepts are understood as residing within fields of power and knowledge that only gain legitimacy by being constantly performed by subjects in the social. However, the performance and constant need to maintain the home discursively was not always clear in the data; frequently patients and carers suggested that district nurses did not affect the home:

> *"Interviewer: Do you think district nurses coming in affects how your home feels?*
>
> *P9: No.*
>
> *Interviewer: No?*
>
> *P9: No. Not in any way, shape or form, no. The dog barks. We've got to put him in the kitchen. We let him out and they pat the dog and what-have-you when the excitement has died down."*

However, such 'no affect' within a post-structuralist reading can be challenged as there must always be some form of continual construction taking place via extant discourses. This is in line with the work of Massey (2005) who suggests

space is continually constructed in a similar way to how Butler suggests subjectivity is, and for both of these authors it is frequently only when disruption occurs that the performative nature becomes apparent:

> *"Interviewer: I'm wondering how you feel about nurses coming into your home?*
>
> *P20: Doesn't bother me anybody coming in to my home as long as I invite them in. If I invite them in and they respect the home when they come in that's no problem."*
>
> -------
>
> *"P2: friendliness sort of stops it affecting how your home feels really."*

Qualifying the interaction with the district nurses in ways such as 'inviting' and 'building friendships' suggests that performances are needed to maintain the home, and that patients and carers may have maintained some modicum of control over the home. However, the power and knowledge that patients and carers had to reform the home environment remained lacking, this was particularly true in relation to the use of technology in the home. For example, home intravenous services which are cited as potentially transformative for patients' and carers' experiences of care at home:

"P14: there is supposed to be an IV service set up and the

district nurses are supposed to be going to do the evening ones

I think… it would be alot better if I could have them at home

rather than at hospital, because you'd probably get it at a better

time, you wouldn't have the chance of picking up another

infection, and you can do things at your own pace at home,

where if you're on a medical ward, you know, it's like yourself,

it's midnight before you're getting your ten o'clock IVs and then

six o'clock when you're getting your next lot. So hoping with an

IV service it won't be that, I can manage it better. Plus it's less

stressful if you're at home."

As such, at home IV care offered the fantasy for this group of patients (IV care was not available across any of the healthcare trusts that patients resided in) of ameliorating the loss of independence associated with and at times expected with illness and hospital care as none of them were offered IV therapies at home. However, the way in which IV services are thinkable by but not achievable for patients demonstrates eloquently that whilst discourses of IV home care somehow circulate to patients and carers the power and knowledge to regulate the boundaries of what the home can contain are not legitimately within patients' and carers' remit. Instead what was more frequently the case was that patients and carers were unable to even think beyond the extant discourses performed by the district nurses:

"Interviewer: Is there anything extra that…So I suppose in an ideal world, not necessarily they do now, or you can see them doing, but is there anything in an ideal world that you think district nurses could do to help keep you out of hospital?

P19: I don't know, not sure. I can only think of if, that they come to see, I don't know, I'm not sure, I don't know.

Interviewer: I mean one thing that a previous person mentioned is giving IV medications.

P19: Oh right.

Interviewer: Now I'm wondering how you feel about that being done at home rather than hospital?

P19: Yes, I'd rather have that done at home, yes."

Whilst this form of questioning could be considered as 'leading' it is important to reject such notions. Instead, this form of questioning was aimed at examining how patients were able to think about their district nursing service in relation to the home, examining how novel suggestions outside of their current discursive regime were received. In this case, it appears that the extant discourses are restricting thinking away from IV therapies (or any other interventions), even though once it was mentioned P19 was relatively

enthusiastic about that possibility. Such restrictions on thinking are an example of the way in which power and knowledge form subjectivities but also shape understanding of the material environment whilst simultaneously covering up the formative work of power and knowledge. Considering the morality of this further with post-structural theory offers space to rethink the ways in which subjects are maintained in relation to the material (in this case the home), as well as other subjects whilst avoiding assuming that the material has some natural quality that gives it meaning outside of discourse to inscribe subjects with meaning.

As demonstrated empirically and theoretically above, the home is in a constant process of being constructed, but that construction is occurring within extant fields of power and knowledge. Hence, one could argue that whilst a subject may give the material its meaning, this meaning is not first given by the subject it gives meaning to. To do so would assume that subjects can give meaning before they are subjects, or that the material has some god like agency. Instead, subjects must first logically become an acting subject within a material world before they can imbue meaning into the material. Hence, extant discourses which are performed by others must imbue meaning into the material which the subject can then access to perform in a relationship to the material environment. Understanding the material in this way turns it into a performative production which is invested with meaning, creating ties and relations that act in a reflexive and circular manner between other subjects and the material. This has two key implications in terms of morality firstly, if

one were to act immorally towards the home, and the home affects subjects, then moral actions must not only include actions towards subjects, but also actions towards the material, in this case patients and carers, and the home.

The effect of district nursing on the material environment of the home occurred in a variety of ways. For example, there were examples of strategies where nurses tried to minimise their effect on the material environment of the home through strategies that sequestered the district nurses' physical presence to specific times and places:

"P12: I used to get things ready for them [district nurses], I used to get the box out and the folder"

"C7: they had a box with all their things in but that was really was about it.

Interviewer: Did you ever go into that box out of interest or was a just a bare box?

C7: No, no… even now we have the box on the small bedroom bed"

However, there were also cases where such sequestering of the material effects of district nursing could not occur and the effects of district nursing resided in the home even when they are not present; for example lounges became bedrooms. Such permanent and material alterations to the home appear to be the beginnings of the type of actions that Liaschenko considers to be morally problematic. However, disruption to the home was not viewed in this way by patients and carers:

> *"C7: To me it would be more of an intrusion, P7 going in hospital, he wouldn't want to go there…he wanted to stay at home."*

The above sentiment was expressed on several occasions; even though district nursing did disrupt, intrude, or alter the home, the home was far more radically altered when someone went to hospital. Hence, it is possible to conclude that technology actually offers opportunities for the home as a place of care to expand, rather than be radically shifted; or to consider it in the moral philosophy terms outlined earlier we could consider that the home and the patients and carers within it can become-other through the use of technology. Therefore, technology and district nursing in home care are not intrinsically morally problematic, as has been previously suggested. Instead producing a becoming-other of the home is preferable to being removed from the home. However, what remains problematic from a post-structural moral philosophy perspective is how power and knowledge circulate to reform the home as a

place of care. As already demonstrated in this and other papers (Nagington et al. *In press*), patients and carers frequently lack knowledge and hence power in relation to district nursing.

What then may be done to expand patients' and carers' power and knowledge in the home? For such discussion turning to Dean's (2009) work on gay male subcultures, with particular reference to his approach to the material environment, is productive. Dean highlights in his work that relationships between subjects and material spaces can also be thought of as being mediated through broader legal and policy directives. In his work on the barebacking (condomless anal sex) sub-cultures Dean suggests that wider political frameworks can direct the way in which spaces are available for various communities to exist, such as in his work with the gay male barebacking community. Such an approach links with Butler's (1990, 1997b) notions of a viable social being through performing discourses but extends it to help develop an understanding of how the viability of social space is contingent on what performances are available. It also develops Massey's (2005) work by clarifying that spaces are given limits by fields of power and knowledge. Therefore, when considering ways in which patients and carers may become-other in relation to the way in which district nursing effects the home, consideration must also be given to how policy and legislation inscribes the home, of which in the interview data 'choice' was particularly notable as being problematic:

"P18: They said with the advancing years, they need to know would I go in a hospice, would I go in a nursing home, would I go, etc, etc, I said, no, I'd prefer to be at home… with elderly people now, they're tending to go for treatment at home, wherever possible, from the cost point of view, amongst everything else, and, also, from the patient's point of view."

This remains a complex and ambiguous quote. It can be seen that patients are beginning to perform the discourses of increasing home care, described at the beginning of this paper, by accepting the home as the best place of care. That "cost" is accepted as a valid reason (alongside patient choice) suggests neoliberal discourses of efficiency in healthcare are also combining to (re)form home care as a viable place of care, whilst choice is simultaneously eroded:

"P23: I had no choice because I couldn't do the injections myself, and I didn't have anybody to do it for me, so I asked if I could get up in the morning and take it to my surgery, but the doctor says no because they would be nobody there to give it to me at weekends. So that's how come I had the district nurse in."

The subjective positions made available become characterised by inevitability and lack of choice along with concerns for economic efficiency.

Conclusions

District nursing and technology in relation to palliative care can be characterised as a complex, inter-relating, and also resolutely non-linear. The home as a space clearly interacted with district nursing and technology, but what conclusions can be made about the morality of these interactions if they are thought of as a process of becoming-other?

Firstly, district nursing and technology should not be thought of as affecting the home, but instead can be considered to become part of the home. As demonstrated in the empirical data, district nursing becomes 'vital' to patients and carers remaining at home. Hence, district nursing must consider how the discourses which they perform not only contribute to but also maintain and become part of the material environment of the home. As discussed above, there were discourses that when performed placed particular boundaries on the meaning of the home as a viable place of care. The home as a site of care was frequently controlled by extant policies on what is or is not routinely provided, such as IV antibiotics, resulting in the home becoming an unviable place of care in the communities that were studied in the UK. The morality however is contingent on the ability of patients and carers to expand the home as a site of care, to become-other. Whilst policy and research alludes to the possibility of choice in end of life care and death, previous research has demonstrated that the power and knowledge that patients possessed to instigate these choices is frequently lacking (Nagington et al. *In press*), rendering choice as a relatively powerless discourse in the face of medical

discourses. In addition, Dean's (2009) work highlights how broader social factors come to effect the material environment. As such, policy needs to move away from ideas of choice and medical best practice, as well as placing less emphasis on increasing in home deaths as a means in itself of achieving quality. Instead there needs to be a focus on approaching home care in a way that allows patients and carers to develop and control understandings of what their individual home is, what boundaries they place on it, and how these boundaries may need to shift with a minimal focus placed on what is 'routinely done' (i.e. what is within the remit of extant discourses). A more non-hierarchical form of co-operative negotiation (both at an individual level, as well as within local and national policies) would be required to achieve this where the home and care is performed, without automatic recourse to either national targets or medical discourses of best practice that preclude a becoming-other of material environment and in turn patients' and carers' subjectivities. Alternative discourses that may help the home become-other may include (but are certainly not limited to), recognition of the importance of being around family, the way in which the home contributes to forming subjectivities, and kinship ties as ways of sustaining patients' and carers' identities.

Finally, as discussed at the beginning of this article, technology has been oppositionally conceptualised as making the home more hospital like. However, the authors wish to suggest that if the power and knowledge to control the technology in the home is moved away from medical or economic

efficiency discourses, and instead incorporates the legitimate use of technology as something which can be connected to ideas of facilitating patients priorities, then the hospitalisation of the home may be revealed as a false dichotomous choice. Hospital and home and the intersection of technology in their reformation may instead cease to be thought of as oppositional and instead a position adopted towards material space that is less about naming space as one binary thing or another, but instead as a moral endeavour reliant on producing rather than precluding the becoming-other of the subjectivities that inhabit the space.

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Box 1 – Inclusion/exclusion criteria

Inclusion criteria
All participants
Over 18 years old
Able to consent
Able to participate in an in-depth interview
Patients only
Receiving or requiring palliative or supportive care
'Active' on a district nursing case load
Exclusion criteria
All participants
Current contact with the researchers in a professional or social capacity
Resident of a nursing or residential home
Carers only
Professional care staff of the patient
Patient declined to be interviewed.

Box 2: Summary of interview topics

Summary of interview topics
General experience of district nurses
Relationship with district nurses
Time keeping of district nurses
Experience of care at home
Continuity of district nursing
Previous contact with district nurses
Previous knowledge of district nurses
Discussion of district nurses with others
Use of touch by district nurses
What do patients do for district nurses
Information sheets about district nursing