



Notes from the hospital bedside: Reflections on researcher roles and responsibilities at the end of life in dementia

Journal:	<i>Quality in Ageing and Older Adults</i>
Manuscript ID	QAOA-09-2016-0038.R2
Manuscript Type:	Research Paper
Keywords:	Dementia , End of life , Researcher reflexivity, Ethics, Pain , Life review

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Abstract

Purpose: This study explores some of the ethical and practical dilemmas faced by an experienced researcher in undertaking research with a person with dementia [whom we have called Amy]. Amy died shortly after a period of observation had ended and the family subsequently consented to the data being shared.

Design: This individual case study presentation was nested within a larger study conducted in England and Scotland between 2013 - 2014. The overall aim of the main study was to investigate how health care professionals and informal carers recognised, assessed and managed pain in patients living with dementia in a range of acute settings.

Findings: The presented case study of Amy raises three critical reflection points: i) Researcher providing care, i.e. the place and positioning of compassion in research observation; ii) What do the stories mean? i.e. the reframing of Amy's words, gestures and behaviours as (end of) life review, potentially highlights unresolved personal conflicts and reflections on loss; and iii) Communication is embodied i.e. the need to move beyond the recording of words to represent lived experience and into more multi-sensory methods of data capture.

Originality: Researcher guidance and training about end of life observations in dementia is presently absent in the literature and this case study stimulates debate in a much overlooked area, including the role of ethics committees.

Keywords

Dementia, end of life, researcher reflexivity, ethics, pain, life review

Funding

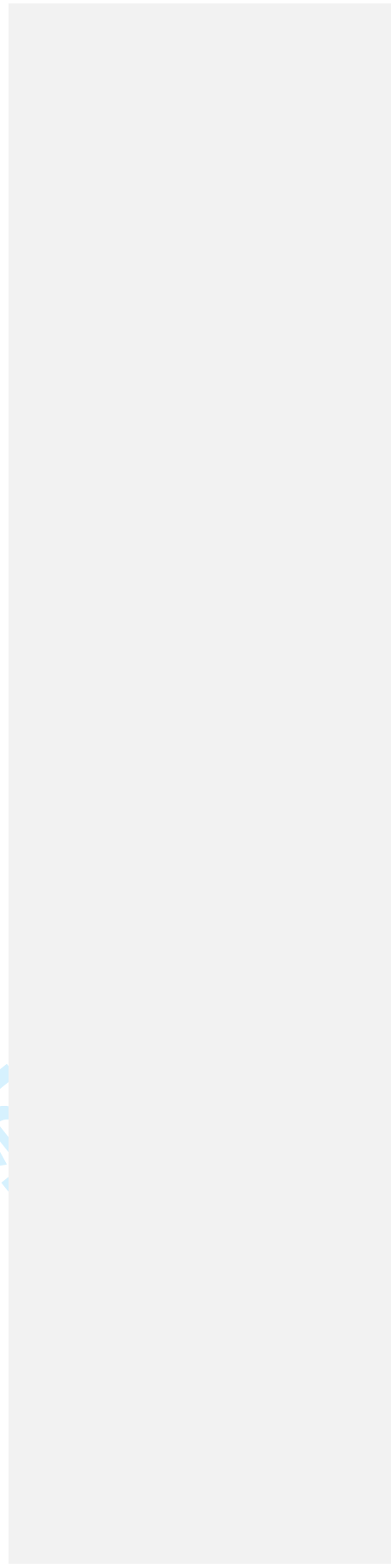
This work was supported by the National Institute for Health Research (NIHR) under its Health Services and Delivery Research (HS&DR) programme (grant reference number 11/2000/05). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

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Declaration of Conflicting Interests

The author declared no potential conflicts of interest with respect to the research, authorship and / or publication of this article.

Quality in Ageing and Older Adults



Introduction

Dementia is currently receiving unparalleled attention in policy, practice, service, academic and community-based arenas. The reasons behind this increased attention are multi-faceted but, arguably, they can be described in three broad domains. First, the escalating prevalence rate of dementia is a global issue with over 46 million people currently living with dementia (Alzheimer's Disease International (ADI), 2015). It is estimated that these figures will almost double every 20 years, reaching around 131.5 million by 2050 (ADI, 2015). In the United Kingdom (UK), national prevalence data suggests that there are currently 835,000 people who have a dementia-type illness (Alzheimer's Society, 2014) with this number predicted to reach over two million by 2051 (Alzheimer's Society, 2015). Second, the significant financial expenditure attributed to dementia with the second *Prime Minister's Challenge on Dementia* (Department of Health (DH), 2015) calculating that during the next 30 years, in the UK alone, costs attributed to dementia are likely to reach over £50 billion. Third, the absence of a cure has led to a pronounced focus on psychosocial approaches to supporting people living with dementia and their peer networks (Guss *et al.*, 2014; Dugmore *et al.*, 2015).

Set against this backdrop, dementia is seen as a clinical and progressive transition through mild, moderate and advanced stages with age being the most significant risk factor for the onset of dementia (Kenigsberg *et al.*, 2016). For example, one person in five over the age of 80 has a dementia-type illness, of which Alzheimer's disease is the most common amongst younger (under the age of 65) and older people (Alzheimer's Society, 2014). Moreover, research shows that 70% of people living with dementia also live with at least one other long-term condition, such as diabetes (All-Party Parliamentary Group on Dementia, 2016) and recent estimates suggest that in the UK alone around one in four acute hospital beds are occupied by a person living with dementia (Alzheimer's Society, 2015). On this latter issue, studies have consistently found that people living with dementia in such settings receive less pain relief for their symptoms (Jensen-Dahm *et al.*, 2016) and remain in hospital for longer than other patient groups (Lichtner *et al.*, 2015). Moreover, a systematic review of assessment tools to identify pain and dementia also revealed a limitation to their existing formulation insofar as there is a lack of biographical representation and personal narrative (Lichtner *et al.*, 2014).

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7 The second Prime Minister's *Challenge on Dementia* (DH, 2015), which runs through to 2020, has
8 acknowledged that '*more needs to be done to ensure that all areas offer high quality end of life care*
9 *for people with dementia*' (p.36) and that it is essential '*to enable people with dementia to one day 'die*
10 *well*' (p.10). Despite the complexity of identifying the end of life trajectory in dementia (Authors A;
11 Lawrence *et al.*, 2011), compassionate care is seen as the vehicle to drive forward this ambition
12 expressed through various palliative models of support (Evans, 2009; Goldberg and Harwood, 2013).
13 Compassionate care has also received significant attention in defining what constitutes high quality
14 nursing care (Scerri *et al.*, 2015) and as a central pillar to defining patient outcomes at the end of life
15 (National Council for Palliative Care, 2010).
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22 Although these are important and necessary steps in care management and service delivery, we
23 could not find any similar studies, or comparable literature, that shared a researcher's experience and
24 responsibilities when a person living with dementia is nearing the end of their life and when consent
25 (proxy or otherwise) to report on the process was in place and supported by a research protocol. This
26 article is intended as a first step in stimulating and articulating a debate in this area. In the case study
27 that follows, the person living with dementia died in the same hospital bed and ward within 24 hours of
28 the first research observation being completed. The death was unanticipated at the onset of the
29 observation period and the case study is shared with the full support and agreement of the
30 participating family. However, some contextual details have been changed to protect the identity of
31 the person living with dementia [whom we have named Amy in the case study] and to comply with the
32 research protocol and ethical permissions.
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42 **Study methods**

43 The main study - from where the following case study is drawn - involved multiple case sites in
44 England and Scotland with embedded units of analysis comprising of individuals, wards and
45 organisations and approached using ethnographic methods. The overall aim of the main study was to
46 investigate how health care professionals and informal carers recognised, assessed and managed
47 pain in patients living with dementia in a range of acute settings (Authors B). The purpose of the study
48 design was to describe phenomena within their real life context and appropriate to exploratory
49 objectives. Four case sites across England and Scotland (NHS hospital trusts, each with one or more
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7 hospitals) were sampled to provide varying settings for acute care. Wards from differing specialisms
8 were selected in each hospital to build up a broader picture of the facilitators and barriers to effective
9 pain detection, assessment and management.
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13 Data collection was undertaken by a different researcher at each of the four sites. In each case site, a
14 variety of data collection methods (including interviews and data from medical and nursing notes)
15 were used to provide multiple sources of evidence for addressing the primary research aim.
16 Furthermore, non-participant observation of health care professionals (HCPs) and health care
17 assistants (HCAs) interacting with patients living with dementia was undertaken in order to explore
18 how pain was detected, assessed and managed by healthcare staff. Non-participant observation of
19 patients frequently evolved into participant observation, as patients often initiated social interaction
20 with the researcher. Observations were framed around a study observation protocol, which included
21 whether or not the patient appeared to be in distress and how this manifests itself.
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29 Inclusion criteria for patients to be involved in the study were aged 65 or over with a recorded
30 diagnosis of dementia. During patient recruitment, we did not distinguish between different degrees of
31 pain or types of dementia. In total, 31 patients (11 men and 20 women; mean age 88, range 75-99)
32 were observed over the 4 case sites during the data collection period (May 2013-July 2014) with over
33 170 recorded hours of field observations and associated case record reviews; 52 interviews with care
34 staff; and 4 interviews with carers (see Dowding *et al.*, 2016 for further details on the overall study
35 design).
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42 Ethical approval was obtained for both English (REC reference: 12/YH/0363) and Scottish (REC
43 Reference 13/SS/0006) sites. The participant consent process was developed to conform to the
44 Mental Capacity Act (2005) and the Mental Health (Care and Treatment) (Scotland) Act (2003).
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46 Patients' consent to participate was subject to capacity assessment to consent (which was initially
47 through consultation with staff and then undertaken by the researcher prior to participant
48 involvement), ~~consultation with staff~~ and assent of carers. Written consent by patients, or agreement
49 from the carer for the researcher to approach the patient, was obtained for all participants. Written
50 consent was provided by all interviewees. The NHS Trusts participating in this study granted access
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7 to the researchers, who complied with local requirements for data collection. All data were
8 anonymised at the point of data collection.
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11 The following case study is taken from one of the hospital sites with the observation performed by a
12 female Research Fellow [*author initials blinded*-lead author]. It is focussed on a patient called 'Amy'
13 who was admitted to an elderly medicine ward after a fall at home two days previously. Prior to
14 admission, Amy lived with her husband at home supported by her family and had lived with a
15 diagnosis of Alzheimer's disease for around eight years. Amy was 84 years of age at the time of
16 admission (mid-July 2014). Amy lacked the capacity to consent and following the study protocol, the
17 next of kin (as Personal Consultee) was approached to give agreement for the researcher to
18 approach the patient. After a 24-hour period of reflection on the provided study information sheets and
19 a further meeting with the family at Amy's bedside to address any points of concern / clarification in
20 the study aims, the family remained keen to support the research aims, potential publications and all
21 necessary agreements were obtained.
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30 The scheduled observation of Amy took place the day after agreement was given. In the case study,
31 the researcher's observation notes are structured around an initial impression of the ward followed by
32 a series of notes collected over a two and a half hour period. The observation notes have a
33 designated start time to illustrate the natural flow of the encounter and are written using a first person
34 narrative. The observation notes are then followed by a series of three critical reflection points drawn
35 directly from the case study and some of the practical and ethical dilemmas faced during the period of
36 data collection. The interpretive framework for the observations was guided by the four-stage
37 analytical principles described Morse (1994).
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45 **Notes from the hospital bedside**

46 **Initial impressions of the ward:** The ward is located in a separate building from the main hospital
47 and is next to the main car park. None of the wards have names and are referred to in a letter –
48 number format. As I enter the ward, I note that there are five bays with six beds each and four
49 separate 'side-rooms'. No communal spaces exist on the ward, but there are a number of individual
50 consultation rooms and staff offices all assigned to senior staff and situated in the corridor by the main
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7 ward entrance. All of these individual doors are closed and look the same. Each bed on the ward is
8 occupied and visible. It is a mixed sex ward although the bays are segregated by gender.
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11 In each of the bays, three beds are set against one wall and three against the opposite wall,
12 positioned with the bed-ends directly facing one another. Privacy only happens if the curtains are fully
13 drawn around the bed; however, the spoken word and noises of the body easily carry beyond this
14 artificial 'private space'. There are windows behind three of the beds; the top panes of glass can be
15 marginally opened and are transparent. These windows connect the six patients to the world outside;
16 however, given the ward's location on the third floor, their only view is of the sky, unless the person is
17 either sitting up or standing up next to one of the windows. All six beds are neatly and regimentally
18 separated by an identical small cupboard and a plastic-coated armchair, which also mirrors every
19 other ward in the building.
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27 Amy is positioned in the bay opposite to the nurses' station. The bay is very warm and each of the
28 windows is about one third open: the maximum possible for safety reasons. The window blinds in
29 Amy's bay are concertinaed and offer little protection against the steadily intensifying sunlight. There
30 is a continuous stream of staff walking towards, around and stopping at the nurses' station opposite
31 Amy's bed. All wear name badges that cannot easily be read and all wear uniforms of various colours
32 and shades of the same colour, denoting different levels and disciplines of staff. The majority of staff
33 on the bay are women. I feel overwhelmed by the suppressive task-oriented atmosphere.
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40 **Time: 10.55:** I arrive at Amy's bedside. Amy is awake, agitated and very distressed. Her false teeth
41 are missing. A HCA is passively sat on a chair next to Amy's bed, but a little too far back for Amy to
42 see her properly. I am not even convinced that Amy is aware that the HCA is there. I introduce myself:
43 first to Amy, and second to the HCA who informs me that her name is Jane. Jane returns a smile and
44 immediately gets up to leave, offering me her vacated chair. Jane goes to sit silently with another
45 patient on another part of the bay. Our paths do not cross again. I walk around the bed to the empty
46 chair and pull it forwards and towards the bed so that Amy can see me and we make eye contact. I
47 introduce myself by my first name and ask if she minds me sitting with her. She smiles at me. Amy
48 immediately starts to shout loudly for 'Alice'. I calmly ask who Alice is and she shouts 'Mam, Mam'.
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7 Amy starts crying and instinctively I reach out and stroke her hair and hold her hand, which she grips
8 tightly. Amy stops crying and looks directly into my eyes. I ask her if she minds me stroking her hair,
9 to which she replies 'it's lovely'. I carry on and Amy continues to shout for 'Alice', whilst looking
10 towards the corridor at the end of the bay. Suddenly, she stops, turns her head to me and says very
11 matter-of-factly: 'they tried to cut him out, but he wouldn't open his eyes'.
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16 **Time: 11.15:** Amy is becoming increasingly distressed, but I continue to stroke her hair serenely. Amy
17 looks frightened and puts her left hand on my right arm whilst I hold her other hand. Once again, Amy
18 looks directly into my eyes. It is a penetrating gaze, almost as if she is questioning who I am,
19 searching for clues, comfort and points of connection between us both. I smile at Amy and, in return,
20 she relaxes and calms a little. Suddenly, she breaks the silence and shouts 'Dad' at the top of her
21 voice, shifting her gaze from me to the corridor at the end of the bay. Instinctively, it feels like Amy is
22 directing her gaze in search for answers, ~~to an unresolved conflict~~ although I do not know the
23 questions. Amy's brow becomes furrowed, her body alert and her facial expression, for want of a
24 better adjective, expectant. I ask Amy her father's name and she whispers to me 'Joseph' in a calm,
25 controlled voice. I ask Amy the colour of her mother's eyes and she replies 'bluey green'. Seemingly
26 trapped in a moment of remembrance, Amy stopped shouting and her tears stopped flowing.
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35 **Time: 11.30:** Amy starts to become very 'fidgety' and unsettled again. She pulls her bedcovers off
36 and pulls her nightdress up, an act that subtly exposes her genitalia. To protect Amy's dignity, I
37 quickly reach over and pull the bedcovers back over Amy. She then starts to scream very loudly,
38 shouting 'Mam, Mam' at the top of her voice. Her gaze darts around the room in a distressed manner.
39 In a calm and soft voice, I continue to reassure Amy predominantly through physical touch, of which
40 she is responsive. I am not sure how much she is aware of my presence. I stroke her hands and face.
41 Amy looks at me and smiles. She puts her right hand on my right hand, which I receive affectionately.
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48 **Time: 11.45:** The sun continues to stream into the bay. Ward rounds are about to begin and the ward
49 is the busiest it has been since my arrival. Amy is still in bed and is talking about someone she once
50 loved. She calmly whispered the words 'it was forbidden back then'. Amy then starts to sing. I do not
51 recognise the song, but Amy has a lovely voice and is clearly enjoying singing, seemingly taking her
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7 to a place that is safe and secure. Amy's forehead relaxes and this time she reaches out to grab my
8 right hand and place it against her left cheek. I gently lower my face towards hers, which, despite my
9 presence in a research capacity, feels a natural and 'right' thing to do. For the first time in a while, one
10 of the nurses positioned by the nurses' station looks over and smiles. Once Amy has finished the
11 song she gets very distressed again screaming at the top of her voice '*Alice, Alice, Alice, Mam, Mam.*
12 *Where are you Mam?*' She then pulls her bedcovers off and attempts to get out of bed, still screaming
13 loudly. I am not convinced that her fragile body would allow her to stand independently. Once again, I
14 endeavour to protect Amy's dignity by putting the bedcovers over her and encouraging her to stay in
15 bed. Suddenly, she starts to cough violently and says she is going to be sick. I alert the nurse who is
16 standing at the nurses' station, but by the time the nurse returns, Amy had coughed something up,
17 spitting the phlegm and fluid on the bedcovers then vigorously - and studiously - wiping the
18 expectorant into the linen with her fingers so that it disappears.

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27 **Time: 13.10:** I ask Amy if she would like some water and she moves her head up and down to
28 indicate 'yes'. I pour her some water into a cup. Amy takes a sip and then returns the cup to me and
29 starts shouting '*Alice, Alice why did you do it? I loved him*'. I stroke her hair and hold her hand,
30 providing as much reassurance as I can. Amy remains very distressed, screaming and pulling at the
31 bedcovers. I remain calm in my responses. Amy then turns her face to mine and says in a still yet
32 pleading voice: '*Oh Mam, why won't you help me?*' ~~For a moment, I feel that she sees me as her~~
33 ~~mother. I am unsure whether this is because my actions of stroking her hair and holding her hand~~
34 ~~symbolise the safety and security often represented through maternal relationships.~~

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42 **Time: 13.15:** Two occupational therapists enter the bay and come over to Amy's bed. They look
43 directly at me and ask if I am Amy's granddaughter. I say '*no*' and explain my role. The therapists say
44 they were expecting her daughter to be present and whether I could let them know when Amy's
45 daughter arrives. Unsettled and confused, Amy looks directly at the therapists as they walk out of the
46 bay without making any verbal or visual contact with her. Once they had left, Amy settles and starts to
47 sing again, very peacefully, and I continue to stroke her hand. She looks at me and briefly closes her
48 eyes.
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7 **Time: 13.20:** Amy continues to sing and I put my face towards hers and smile. We look at each other
8 and are lost in a moment of human connectedness. Amy breaks the connection and I look to the side
9 of the bay and see Amy's daughter arriving. I recognise her daughter from our meeting on the
10 previous day. I let Amy know that her daughter is here and deliberately point towards the bottom of
11 the bed where her daughter is now standing. Amy's gaze follows my outstretched finger, with little
12 outward recognition. I do not know if she recognises her daughter. I thank Amy for letting me be with
13 her today. She smiles. I say *'goodbye'* and leave her bedside. As I get to the entrance of the bay,
14 Amy's husband is gradually making his way towards his wife's bedside. He is using a walking stick
15 and looks both emotionally fragile and physically frail. When he sees Amy his chin begins to quiver
16 and his eyes well up. I thank him for allowing me the privilege of spending some time with his wife.
17 His gaze remains forward-facing, displaying such strength and love for his wife. **Observations end at**
18 **13:25 for visiting time.**
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27 **Critical Reflection Points**

28 **Reflection Point One: Researcher providing care.** The 'instinctive' reaching out to Amy, both
29 physically and emotionally, was something that was unplanned, unrehearsed and, for the (female)
30 researcher involved, came from a place of compassion and long-standing immersion in interpersonal
31 work with people living with dementia and their support networks. However, as a mixed gendered
32 research team, we had not written anything in the research protocol, or in the patient information
33 sheets, that addressed touch and compassion. Indeed, to satisfy the needs of the ethics committee
34 approving the study, the main emphasis in these documents was placed on the protection of
35 vulnerable people from abusive situations and the researcher actions – and reactions – to dealing
36 with such situations, including the provision of a risk register. These objective ways of dealing with
37 issues relating to dementia was, arguably, the polar opposite to the subjective anguish and emotional
38 torment that Amy was experiencing at that moment of time in her life. Human touch and empathic
39 understanding were ways of helping to reassure Amy about her presence in a 'safe' environment that
40 was clearly not her home. The research protocol for the study identified non-participant observation
41 as the method of choice which, strictly speaking, related to the interactions between HCPs / HCAs
42 and patients, not the interactions between the researcher and the patient of which some level of
43 interaction would be considered unavoidable, an experience also encountered by Lawton (2001).
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7 This, therefore, raises issues about the role of the researcher in situations of human distress and the
8 extent to which human compassion should transcend a research protocol (Lawton, 2001).
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13 *Considerations:* 1) The female researcher and female patient dynamic generates a question: do we
14 need to consider gender more carefully in the future, especially when researching / working in such
15 sensitive areas of care practice? 2) To what extent does the professional background of the
16 researcher (in this case, a social scientist) influence the nature of the interaction? 3) Going forward,
17 do we need a new type of research protocol that looks at everyday ethical and compassionate issues
18 and outlines engagement strategies of the researcher in complex and sensitive situations?
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24 **Reflection Point Two: What do the stories mean?** At the time of consent and participation, it was
25 not envisaged that Amy would die at the end of the first planned period of observation. However, she
26 did and with such hindsight, the words, gestures and behaviours that Amy displayed can be re-
27 contextualised against this knowledge and reframed as a life review pursuit. The fact that Amy was
28 distressed and in emotional turmoil during the encounter is not in question; however, the researcher
29 had access to limited personal information about Amy (either from clinical staff or from Amy's family)
30 before stepping into the field and into the encounter. This made understanding the emotive phrases,
31 such as, '*they tried to cut him out, but he wouldn't open his eyes*' and '*it was forbidden back then*',
32 subject to reflective interpretation framed around Amy's words, emotions and expressions. The true
33 meanings of these words were not disclosed and remain privately situated within Amy's life, and
34 death.
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43 *Considerations:* 1) To what extent should a researcher be exposed to certain areas of the individuals'
44 life story prior to entering the field, especially when capacity is a significant issue? 2) Does unresolved
45 emotional pain have the potential to outweigh physical pain at certain time points, particularly the end
46 of life?
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51 **Reflection Point Three: Communication is embodied.** One of the most telling parts of the
52 encounters was that Amy sang a lot during the observation period, which momentarily alleviated her
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distress. Singing represented a path to her inner-reality and the world in which she found herself. The words Amy sang were hard to follow and at times incomprehensible, but she smiled, made gestures and undoubtedly 'musically performed' during our time together. The fact that this performance was in an environment that was unfamiliar to her and had so little to relate to - in terms of familiar possessions, objects, views and people – makes it all the more understandable. This performance enabled Amy to project her identity onto the world around her. The question for research practice is: how do you best capture Amy's communication and interaction experiences?

Considerations: Would video recording Amy during the encounter - instead of making observational notes – have allowed for a more multi-sensory and embodied analysis to be made of the interaction between Amy, her environment, and the researcher?

Discussion

Single case studies have been used over the years in dementia studies to shine a spotlight on unseen areas of care and sensitive areas, such as in dilemmas faced post-bereavement in a spouse carer of a younger person with dementia (Williams *et al.*, 1995), examining the impact of counselling and carer goal-setting post-diagnosis of dementia (Authors C), in caring for a person with rare and unusual dementia such as semantic dementia (Kindell *et al.*, 2014) and HIV dementia (Turner *et al.*, 2016). Whilst this article continues this tradition, it differs in the sense that the benchmark focuses on researcher practice as opposed to the experience of the person living with dementia, family or clinician.

Undertaking research in sensitive areas has long held resonance in qualitative research, with Lee (1993) suggesting that researcher-participant contact should take place on a 'one time' basis, ensuring that participants '*can disclose their experience safe in the knowledge that the paths of the interviewer and interviewee will not cross again*' (p. 112). However, as this case study (and reflective point 2 highlights), it is not the character that is important in the research activity, but the connection of the researcher to the individual (as 'participant'), in terms of both emotional and physical domains. Here, ethics becomes a transcending theme. Amy was experiencing parallel levels of emotional and

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7 psychological distress, whereby human touch was perceived by the researcher as one way of helping
8 to provide a safe and comforting environment.
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11 Watson's (1975) description of expressive touch, offers comfort and reassurance, representing a
12 channel to human connectedness. This discourse is extended through the work of Gleeson and
13 Higgins (2009), who infer that the symbolism of touch enhances '*rappont and emotional connection*'
14 (p.384), whilst expressing care and empathy towards others. According to Nicholls *et al.* (2013) touch
15 for people living with dementia who are at the end of life is '*as important, if not more so*' (p.576) than
16 at any other time in life. Reciprocity is an essential feature of touch and inherent compassion as was
17 demonstrated through the perceived connection between Amy and the researcher. However, the
18 need for such compassion and human connection often conflicts with the traditional role of 'academic
19 researcher' which requires objectivity, independence and human separateness. This role conflict is
20 contested to the extent that the researcher almost adopts a 'caregiver' role in delivering compassion
21 and empathy at the end of life (Teno and Connor, 2009). Additional debate and consensus is required
22 on the influence of human [researcher] compassion on the data and its intersection with analysis.
23 Moreover, given both the researcher and patient were female, a further ethical debate is needed that
24 focuses on the importance of gender and whether, for example, the same response by a male
25 researcher towards a female patient would be deemed as appropriate (Gleeson and Higgins, 2009).
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37 To some extent, resolve of these blurred boundaries may be located in the seminal writings of
38 Kitwood (1997). Whilst person-centred care has become embedded within clinical practice, there is
39 concern that its conceptual underpinnings often become overlooked within the routine of everyday
40 care. Kitwood (1997, p.82) identified six psychological needs of people living with dementia, those of:
41 comfort, attachment, inclusion, occupation, identity and love. Interestingly, these specific needs
42 resonate with the best practice recommendations put forward both by the National Institute for Clinical
43 Excellence / Social Care Institute for Excellence (2006) and later, the Nuffield Council on Bioethics
44 (2009), the latter of which places emphasis on '*caring for the whole person*' (p.55). Whilst these needs
45 were clearly apparent for Amy, the translation and embodiment of person-centred care and human
46 connectedness within our own academic practice is not so straightforward. The Research
47 Governance Framework for Health and Social Care (DH, 2005) clearly states that the '*dignity, rights,*
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7 safety and well-being of participants must be the primary consideration in any research study' (DH,
8 2005, p.7) and highlights the researchers' responsibility of 'ensuring participants' welfare while in the
9 study' (DH, 2005, p.23). But with Amy's case study as a context, what does this actually mean when
10 the researcher is faced with individual human distress on a busy ward environment and do we need a
11 person-centred set of ethical rights and responsibilities for the researcher when conducting work in
12 such sensitive areas? The situation is complicated further as the Mental Capacity Act (2005) makes it
13 clear that we should not avoid such sensitive areas of research, particularly for those who may not
14 have the capacity to give consent for participation: 'If subjects whose mental state is both the subject
15 of inquiry and the reason for lack of capacity are excluded from study then knowledge cannot
16 advance satisfactorily' (Adamis *et al.*, 2005, p.138). In addition, we would hope that participating in
17 research has a wider benefit to people with dementia (DH, 2005) and the Mental Capacity Act (2005,
18 p.207) states that 'the aim of the research must be to provide knowledge about the cause of, or
19 treatment or care of people with, the same impairing condition – or a similar condition'.
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29 A key aspect of this case study is how Amy, herself, benefited from her participation in research.
30 Despite the best efforts of staff, Amy was mainly alone (until her daughter and husband arrived) and
31 appeared to be comforted by her interaction with the researcher. For the researcher, and for the
32 research team as a whole, it would appear that we fulfilled the requirement in the Mental Capacity Act
33 (2005), namely that: 'the research must have some chance of benefiting the person who lacks
34 capacity and that ... the benefit must be in proportion to any burden caused by taking part' (p.207).
35 Advanced dementia nearing the end of life can cause human - distress (Robinson *et al.*, 2005) and no
36 set of carefully constructed words can soften that reality. From our experience in being alongside Amy
37 in the last day of her life, we put forward the idea that empathy and human compassion in research
38 involving people with advanced dementia should play a central and disclosed role in future research
39 practice and one which must, we would suggest, be present and visible in the research protocol.
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48 The shift from non-participation to participant observation went beyond verbal interaction towards
49 physical interaction (touching hands, face and stroking hair). Whilst participant observation (Kayser-
50 Jones, 2002; Smebye and Kirkevold 2013) and non-participant observation (Porock, et al. 2013) are
51 commonplace within the dementia research field, the extent of the shift by the researcher was
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7 deemed necessary in response to the construed distress of the patient. This approach has previously
8 been described as a 'hybrid participant / non-participant approach' (Norman, 2006).
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11 Finally, acknowledging the more general considerations and recommendations put forward by Gysels
12 *et al.* (2013) and Sivell *et al.* (2015), which focus on the technical aspects of consent rather than the
13 process itself, the authors suggest that the current paper is considered as a starting point for more
14 specific knowledge generation and reflection for researchers engaged in this process, or when the
15 potential for end of life is a risk factor. The discord between having a research and 'clinical' role has
16 been highlighted in the wider field of palliative care research (Stevens *et al.*, 2003) and also between
17 the paucity of data that we have and the necessity to improve end of life care. This was reinforced by
18 the Neuberger report into the Liverpool Care Pathway which recommended that there should be
19 increased qualitative and detailed studies of the dying process (Independent Review of the Liverpool
20 Care Pathway, 2013). However, it would seem that the ripples stemming from such a statement have
21 not addressed the role and responsibilities of the researcher and ethics committees in the
22 complexities that arise from such qualitative study. Dementia care and researcher ethical
23 responsibilities are more than the protection from abuse, as important as that topic manifestly is.
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32 33 34 **Study limitations**

35 This paper reports on a single patient in a single site with observations undertaken by a single
36 researcher. None of the patients in the other sites were at the end of life and therefore, experiences
37 were not reflective of other researchers in the wider study. Whilst the purpose is not to present any
38 generalisable experiences, it raises a number of ethical concerns and debates which, anecdotally, are
39 not unique (or uncommon) to people living with dementia who are at the end of life. Furthermore, this
40 paper outlines the reflections of a single researcher who is experienced within the field. A less
41 experienced researcher, or a researcher who may have assumed a more detached approach, may
42 have opposing reflective experiences. Whilst the researcher had access to support from a senior
43 member of staff, access to debriefing and reflective support is fundamental for any research involving
44 people who are at an advanced stage of dementia and/or nearing the end of life.
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52 53 **Conclusion**

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7 This paper explores the role of human compassion in research, which is all too often viewed in the
8 context of an 'intervention'. As researchers, we tend to centralise the issues of capacity, autonomy
9 and consent, but as seen in the case study of Amy, research occurs within a more 'human' and
10 ethical arena. There is often an assumption from ethics committees that they are 'guardians' of the
11 participants, protecting 'them' from potential risk or harm when, conversely, the opportunity to be
12 involved in research could benefit participants and provide an additional therapeutic / caring
13 opportunity towards the end of life. Notwithstanding such developments, guidance, training and
14 practical application for researchers about this issue is absent and its development is a natural next
15 step in the involvement of people living with advanced dementia in research who are at, or nearing,
16 the end of life.
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27 References

28
29 Adamis, D., Martin, F.C., Treloar, A. and Macdonald A.J. (2005), "Capacity, consent, and selection
30 bias in a study of delirium", *Journal of Medical Ethics*, Vol. 31, pp. 137-43.
31

32
33
34 All-Party Parliamentary Group on Dementia (2016), "*Dementia rarely travels alone. Living with*
35 *dementia and other conditions*", available at:
36 https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=3008 (accessed 5 May 2016).
37
38

39
40 Alzheimer's Disease International (2015), *World Alzheimer Report 2015. The Global Impact of*
41 *Dementia. An analysis of prevalence, incidence, cost & trends*, Alzheimer Disease International,
42 London, UK.
43
44

45
46 Alzheimer's Society (2015), *Dementia 2015: Aiming higher to transform lives*, Alzheimer's Society,
47 London, UK.
48
49

50
51 Alzheimer's Society (2014), *Dementia 2014: Opportunity for change*, Alzheimer's Society, London,
52 UK.
53
54

1
2
3
4
5
6
7
8 Department of Health (2015), *The Prime Minister's challenge on dementia 2020*, Department of
9 Health, London, UK.

10
11
12 Department of Health (2005), *Research governance framework for health and social care*, 2nd edn,
13 Department of Health, London, UK.

14
15
16
17
18 Reference blinded

19
20
21 Dugmore, O., Orrell, M. and Spector, A. (2015), "Qualitative studies of psychosocial interventions for
22 dementia: a systematic review", *Ageing and Mental Health*, Vol. 19 No. 11, pp. 955-967.

23
24
25
26 Evans, G. (2009), "Improving end of life care for the person with dementia", *Dementia: the*
27 *international journal of social research and practice*, Vol. 8 No. 3, pp. 363-376.

28
29
30
31 Gleeson, M. and Higgins, A. (2009), "Touch in mental health nursing: an exploratory study of nurses'
32 views and perceptions", *Journal of Psychiatric and Mental Health Nursing*, Vol. 16, pp. 382-389.

33
34
35
36 Goldberg, S. and Harwood, R. (2013), "Experience of general hospital care in older patients with
37 cognitive impairment: are we measuring the most vulnerable patients' experience?" *BMJ Quality and*
38 *Safety*, Vol. 22, pp. 977-980.

39
40
41
42 Guss, R. and colleagues on behalf of the Faculty of the Psychology of Older People (2014), *A guide*
43 *to psychosocial interventions in early stages of dementia*, The British Psychological Society,
44 Leicester, UK.

45
46
47
48 Gysels, M., Evans, C.J., Lewis, P., Speck, P., Benalia, H., Preston, N.J., Grande, G., Short, V., Owen-
49 Jones, E., Todd, C.J. and Higginson, I.J. (2013), "MORECare research methods guidance
50 development: recommendations for ethical issues in palliative and end-of-life care research",
51 *Palliative Medicine*, Vol. 27 No. 10, pp. 908-917.

1
2
3
4
5
6
7
8 Independent Review of the Liverpool Care Pathway (2013), "More care, less pathway. A review of the
9 Liverpool Care Pathway", available at:
10 https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care
11 [_Pathway.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care) (accessed 21 July 2016).
12
13

14
15
16 Jensen-Dahm, C., Palm, H., Gasse, C., Dahl, J.B. and Waldemar, G. (2016), "Postoperative treatment
17 of pain after hip fracture in elderly patients with dementia", *Dementia and Geriatric Cognitive*
18 *Disorders*, Vol 41, pp. 181-191.
19

20
21
22 Reference blinded
23
24

25
26 Kenigsberg, P.A., Aquino, J.P., Bérard, A., Gzil, F., Andrieu, S., Banerjee, S., Brémond, F., Buée, L.,
27 Cohen-Mansfield, J., Mangialasche, F., Platel, H., Salmon, E. and Robert, P. (2016), "Dementia
28 beyond 2025: knowledge and uncertainties", *Dementia: the international journal of social research*
29 *and practice*, Vol. 15 No. 1, pp. 6-21.
30
31

32
33
34 [Keyser-Jones, J. \(2002\), "The experience of dying: an ethnographic nursing home study". *The*](#)
35 [*Gerontologist*, Vol. 42, Special issue III, pp. 11-19.](#)
36

37
38
39 Kindell, J., Burrow, S., Wilkinson, R. and Keady, J. (2014), "Life story resources in dementia care: a
40 review", *Quality in Ageing and Older Adults*, Vol. 15 No. 3, pp. 151-161.
41
42

43
44 Kitwood, T. (1997), *Dementia reconsidered*, Open University Press, Buckingham, UK.
45

46
47 Lawrence, V., Samsi, K., Murray, J., Harari, D. and Banerjee, S. (2011), "Dying well with dementia:
48 qualitative examination of end of life care", *The British Journal of Psychiatry*, Vol. 199, pp. 417-422.
49

50
51 Lawton, J. (2001), "Gaining and maintaining consent: ethical concerns raised in a study of dying
52 patients", *Qualitative Health Research*, Vol. 11 No. 5, pp. 693-705.
53
54

1
2
3
4
5
6
7
8 Lee, R.M. (1993), *Doing research on sensitive topics*, Sage, London, UK.

9
10
11 Lichtner, V., Dowding, D., Esterhuizen, P., Closs, S.J., Long, A.F., Corbett, A. and Briggs, M. (2015),
12 "Pain assessment for people with dementia: a systematic review of systematic reviews of pain
13 assessment tools", *BMC Geriatrics*, Vol. 14, p. 138.

14
15
16
17
18 Lichtner, V., Dowding, D. and Closs, S.J. (2014), "The relative meaning of absolute numbers: the
19 case of pain intensity scores as decision support systems for pain management of patients with
20 dementia", *BMC Medical Informatics and Decision Making*, Vol. 15 No. 11, p. 111.

21
22
23
24 *Mental Capacity Act (2005), Code of Practice*, Office of the Public Guardian, Birmingham, UK.

25
26
27 *Mental Health (Care and Treatment) (Scotland) Act 2003*, available at:

28 http://www.legislation.gov.uk/asp/2003/13/pdfs/asp_20030013_en.pdf (accessed 26 July 2016).

29
30
31
32 Morse, J.M. (1994), "Emerging from the data: the cognitive processes of analysis in qualitative
33 inquiry", in Morse, J.M. (Ed.), *Critical issues in qualitative research methods*, Sage, Thousand Oaks,
34 CA, pp.23-43.

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35
36
37
38 National Council for Palliative Care (2010), *Priorities for dementia care within the end of life care*
39 *strategy's quality markers and measures for commissioners*, National Council for Palliative Care,
40 London, UK.

41
42
43
44
45 National Institute for Clinical Excellence / Social Care Institute for Excellence (2006), *Dementia:*
46 *supporting people with dementia and their carers in health and social care. NICE clinical guideline no:*
47 *42*, National Institute for Health and Clinical Excellence, London, UK.

1
2
3
4
5
6
7 Nicholls, D., Chang, E., Johnson, A. and Edenborough, M. (2013), "Touch, the essence of caring for
8 people with end-stage dementia: a mental health perspective in Namaste Care", *Ageing and Mental*
9 *Health*, Vol. 17 No. 5, pp. 571-578.

10
11
12
13 [Norman, R. \(2006\). "Observations of the experiences of people with dementia on general hospital](#)
14 [wards", *Journal of Research in Nursing*, Vol. 11 No. 5, pp. 453-165.](#)

15
16
17
18 Nuffield Council on Bioethics (2009), *Dementia: ethical issues*, Cambridge Publishers Ltd, Cambridge,
19 UK.

20
21
22
23 [Porock, D., Clissett, P., Harwood, H. and Gladman J. \(2015\), "Disruption, control and coping:](#)
24 [responses of and to the person with dementia in hospital", *Ageing and Society*, Vol. 35, pp. 37-63.](#)

25
26
27
28 Robinson, L., Hughes, J., Daley, S., Keady, J., Ballard, C. and Volicer, L. (2005), "End-of-life care and
29 dementia", *Reviews in Clinical Gerontology*, Vol. 15, pp. 135-148.

30
31
32 Reference blinded

33
34
35
36 Scerri, A., Innes, A. and Scerri, C. (2015), "Discovering what works well: exploring quality dementia
37 care in hospital wards using an appreciative inquiry approach", *Journal of Clinical Nursing*, Vol. 24,
38 pp. 1916-1925.

39
40
41
42 Sivell, S., Prout, H., Hopewell-Kelly, N., Baillie, J., Byrne, A., Edwards, M., Harrop, E., Noble, S.,
43 Sampson, C. and Nelson, A. (2015), "Considerations and recommendations for conducting qualitative
44 researcher interviews with palliative care and end-of-life care patients in the home setting: a
45 consensus paper", *BMJ Supportive and Palliative Care*, Vol. 0, pp. 1-7.

46
47
48
49
50 [Smeybe, K. L. and Kirkevold, M. \(2013\), "The influence of relationships on personhood in dementia](#)
51 [care: a qualitative, hermeneutic study", *BMC Nursing*, Vol. 12, p. 29.](#)

1
2
3
4
5
6
7 Stevens, T., Wilde, D., Paz, S., Ahmedzai, S.H., Rawson, A. and Wragg, D. (2003), "Palliative care
8 research protocols: a special case for ethical review", *Palliative Medicine*, Vol. 17, pp. 482-490.
9

10
11 Teno, J. and Connor, S. (2009), "Referring a patient and family to high-quality palliative care at the
12 close of life", *Journal of the American Medical Association*, Vol. 301, pp. 651-659.
13

14
15
16 Turner, R.S., Chadwick, M., Horton, W.A., Simon, G.L., Jiang, X. and Esposito, G. (2016), "An
17 individual with human immunodeficiency virus, dementia and central nervous system amyloid
18 deposition", *Alzheimer's and Dementia (Amsterdam)*, Vol 4, pp. 1-5.
19

20
21
22
23 Watson, W.H. (1975), "The meaning of touch: geriatric nursing", *Journal of Communication*, Vol. 23,
24 pp. 104-112.
25

26
27 Williams, O., Keady, J. and Nolan, M. (1995), "Younger-onset Alzheimer's disease: learning from the
28 experience of one spouse carer", *Journal of Clinical Nursing*, Vol. 4, pp. 31-36.
29
30
31
32
33
34
35
36
37
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41
42
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