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TITLE PAGE

Older people's perspectives on dignity: the benefits and challenges of a qualitative longitudinal approach to researching experiences of later life

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Abstract

This article discusses findings from a qualitative longitudinal study of dignity in later life, which focused on the perspectives of older people at a time when their need for help and support was increasing as a result of long-term illness. It reflects critically on the methodology for its ability to generate knowledge about this eventful and unstable period of the life-course. It is argued that a longitudinal qualitative approach provides the optimum conditions for researching older people's perspectives on their health and illness as well as on their experiences of being helped and supported. It sheds light on the changes they faced in their relationships, their home environments and their daily lives as well as how they dealt with these changes while maintaining their dignity.

Introduction

This article presents a discussion of a qualitative longitudinal (QL) study of dignity in later life and reflects critically on the methodology. The study, which was part of the UK New Dynamics of Ageing Programme, took place between November 2007 and June 2012, with 31 months of field work in the cities of Bristol and Nottingham. Thirty four older participants took part, all of whom had long-term serious health problems that had given rise to varying degrees of need for help and support in daily life. The research questions addressed were:

1. What accounts are given about dignity in daily life by older adults?
2. What resources are available to them to draw upon?
3. What factors are perceived to support or undermine a sense of dignity?
4. What preparations do older adults who are facing death at a near but uncertain time make for the process of death and dying?

Rationale for the research design

In the UK, increased life expectancy has typically meant added years spent with complex long-term ill-health, which is often associated with loss of mobility and sensory abilities (Office for National Statistics 2012). The risks are not equally shared. Inequalities in health, illness and life expectancy, related to gender, socio-economic background and other factors, are well established (Nazroo 2015) and are reflected in differences between chronological and physiological ageing. Increasing demand for health and social care services, associated with societal ageing, has generated tensions between the need to contain the *cost* of services and the imperative to promote *dignity* in services. Missing from public debates, however, are the voices of people on the receiving end of support, whose lives have changed profoundly as a consequence of long-term illness.

This project adds to a growing body of research that seeks to place older people's voices centre stage (Buse and Twigg, 2015). There are moral and epistemological reasons for doing so: Grenier (2012, 2006), for example, points to the continuing dominance of medical discourses concerning 'frailty', which contrast with those of older people whose view of frailty is more fluid. Baxter and Glendinning (2013) highlight the complexity of older people's perspectives on choice-making, which is poorly understood by service providers, while Bornat and Bytheway (2010) demonstrate how older people's views of risk in everyday life challenge normal social work practices. Questioning dominant discourses about old age is an important task for researchers, therefore, not only as a matter of social justice but also to develop knowledge of old age that is grounded in experience and challenges institutional assumptions and dominant cultural discourses.

Millar (2007) highlights the potential of QL research to examine the subjective experience of personal change, which in our project involved change in participants' health, which had already begun prior to the study and would continue throughout its duration. Of particular interest was how changing health affected participants' day-to-day lives, living arrangements, social relationships, and perspectives on the future – all of which had implications for their dignity. A QL approach was chosen because it would put us in contact with participants over a defined period within this significant time of uncertainty and would enable us to explore their perspectives on the present and future in the context of their earlier lifecourse.

The concept of the lifecourse emphasises the importance of time, change and continuity within individual lives *as well as* the interrelationship of individual experience and social contexts (Dannefer and Stettersten 2010, Hareven and Adams 1982). It highlights the ways in which particular historical periods and locations shape the experiences of age cohorts as well as differences and inequalities between individuals within these. From the perspective of stage-based, lifecourse research, our participants might be regarded as having made or in the process of making a transition to ‘fourth age’ – the period of life prior to death in old age that is defined by declining health and increasing dependency. Grenier (2012), however, argues that evidence from older people’s accounts shows a variety of individual pathways and thresholds that challenge defined stages. Moreover, as the lifecourse is shaped and influenced by the social and cultural contexts in which we live, it follows logically that there is no standard, measurable threshold between third and fourth ages. In addition, the long-term illnesses that are characteristic of contemporary old age can also mean it is difficult to discern whether an individual is living or dying because of the lengthy and ‘dwindling’ process they experience (Nicholson et al 2012). Thus, the contours of the fourth age are blurred and differentiated. A QL approach enables the researcher to maintain a focus on individual and social levels and, as Neale and Flowerdew (2003) argue, gives a sense of the dynamic nature of life and the interplay of temporal and cultural dimensions.

How long a longitudinal study lasts is an important question (Corden and Millar 2007, McLeod 2003). Saldana (2003) argues that in deciding the 'right' length, each study must take into account its aims and context. In this study the maximum period of participant involvement was 2 years and 7 months. In deciding the length, we had to consider the demands of a longitudinal study and their potential effect on people poor health as well as the possibility that fewer would have signed up to a lengthier study. We calculated that within 30 months there would be sufficient points of contact with appropriate intervals between these to enable us to capture the data we wanted without overburdening the participants.

Methodological and ethical questions

A number of inter-related methodological and ethical questions arose in the process of designing the project. A key point made by Neale (2013), relates to time itself. Apart from the time participants gave to the project, the interview questions were strongly time-related, focusing on participants' earlier lives, recent past and present circumstances as well as the future, which, given their health problems, might look bleak. We considered that participants might be embarrassed about describing their health problems or distressed when talking about death and bereavement. An advantage of QL research, however, is the enhanced potential for trust in researcher-participant relationships, which facilitates discussion of sensitive topics, enabling researchers to judge the optimum moment to raise them. McLeod (2003) argues that openness and fluidity in QL research enables researchers to avoid lines of questioning that might appear confrontational in a one-off interview. Based on our prior collective experience we expected participants to change their views about, for example, where they wanted to live or how they wanted to be supported. We framed our questions accordingly: ‘How do you feel about X now?’ and ‘Since we last met have you thought any more about Y?’

Longitudinal research is demanding of participants’ time and energies and rewards are appropriate (Neale 2013). Our intention to give participants gift tokens was disallowed by the NHS Local Research Ethics Committee but we sent Christmas cards and telephoned between interviews to enquire about events we knew were coming up, such as moving house. We also had a duty to end the fieldwork appropriately and invited participants to events with refreshments so we could thank them for their participation and present our emerging findings. In the final interview, we asked participants why they had agreed to take part and how, on reflection, they felt about their participation. Most said that they had been stimulated by the desire to ‘make a contribution’ that could have a positive effect in future. All said they had enjoyed being a part of the study and some that they had benefited from the opportunity to reflect and ‘unburden’ themselves.

The question of attrition frequently arises in the context of longitudinal qualitative studies (Koro-Ljungberg and Bussing 2013). In this study, we had to consider the possibility that participants’ health would be adversely affected by being involved. We were prepared to stop or rearrange interviews if necessary and asked at each encounter if they were happy to continue with the study. We offered participants the option of selecting a supporter for the duration of the study. Supporters acted as a point of contact if a participant was unable or unwilling to contact us direct and as potential interviewees if a participant was too unwell to be interviewed. All but five chose a supporter, mostly their spouse or partner, but also sons, daughters and friends. The involvement of supporters is a valuable means of facilitating the inclusion of people in poor health in research projects but the longitudinal approach increased the likelihood that their involvement – especially when they were the spouse or partner - became more that of a ‘co-participant’. This sometimes required sensitivity in the interviews as well as care to analyse the data separately.

We were prepared for deaths among the participant group and did not regard these as attrition in the usual sense. On the contrary, we wanted to learn about the ways in which participants were supported through the process of dying and to interview supporters as early as appropriate after the death. Six died during the study but the other 28 remained throughout. We also needed to take account of possible loss of mental capacity and the effect of this on participants’ ongoing consent to participate. All participants gave consent in writing at the outset and verbally at the beginning of each subsequent interview when the researcher checked that the participant was clear about the purpose of the study and their participation in it before proceeding.

After obtaining ethical approval we began recruiting participants through three general practices and two day centres. Response rates were variable: the overall rate from GP recruitment was 20.6% (10%, 22% and 32% across the 3 practices). Calculating response rates from the day centres was difficult, as the invitations were issued openly to people attending at different times. The final group of 34 participants all lived in their own homes at the beginning of the study. Four were in supported housing, 15 lived alone and 19 with their partner. One was of South Asian heritage; the others were white British. There were 21 men and 13 women, which was an unusual gender balance for this age group. To explore possible reasons for this we reviewed our recruitment procedures but were unable to identify an explanation.

Table 1 shows selected characteristics of the participant group at the time of the first interview.

TABLE 1 ABOUT HERE

Mindful of the impact of socioeconomic inequalities, we decided on selection criteria that combined age *and* current health status, with age 75 and over as our target age group (we also recruited one 70 year-old). To enable us to include a range of health and illness trajectories, the GPs recruited participants who fell into three groups. Thirteen had had an unscheduled period as a hospital inpatient in the past twelve months (which can indicate a significant adverse health event) *and* high level need for support with, for example, bathing, dressing or eating or requiring frequent visits from a community nurse. Eight participants had similar support needs but no unscheduled inpatient hospital treatment, while the remaining thirteen had needs for ongoing support at a lower level, such as help with shopping and housework.

Data collection

Participants were interviewed in their own homes between June 2008 and January 2011 by two researchers, each participant being interviewed by the same researcher throughout. Most were interviewed four times, fewer in seven cases because of deaths and serious illness. Nine were interviewed a fifth time because of particular circumstances that we wanted to follow up, such as imminent results of medical tests, or a potential move to a care home. We approached each ‘round’ with particular topics scheduled but also allowed plenty of time for participants to raise their own. The first round focused on participants’ everyday lives, activities, experiences of being supported and their views on ageing and dignity. Data were gathered also on age, marital status, ethnicity, family members, previous employment, tenancy and the length of time they had lived in their home. The second round focused on earlier life (including childhood, work, marriage and relationships) and on participants’ personal values and beliefs. The third focused on changes in participants’ health and circumstances since the first interview, how they had dealt with these and what support they had. In the fourth round, we reviewed and expanded on topics raised previously and reflected on their participation in the study. If the topic of how they saw the future had not already been raised we covered it at this point, asking about future treatment preferences and whether they had discussed these with their GPs or family members.

Initial analysis of the transcripts of each round prior to commencing the next highlighted particular points to be followed up. Smith (2003) argues that this practice sharpens the focus of research. In our experience it enhanced the integrity of the research as a process, rather than as a series of one-off encounters and was also beneficial in terms of building relationship of trust. Thus, when a researcher asked; *‘Last time I was here, you were waiting to see the specialist about …. how did that go?’* participants were encouraged by our interest and attention.

The relaxed approach to interviewing did, however, mean that a lot of time was spent listening, sometimes repeatedly, to participants’ stories. This time was often enjoyable and contributed to relationship building but it had resource implications, the generation of extraneous data taking up researcher time and increasing the cost of transcriptions. The build-up of relationships was a two-way process that, as Neale (2013) discusses, altered the researcher-participant relationship. Listening to accounts of deaths, bereavements and illness could be distressing for researchers. Hurd-Clarke (2013) notes that researchers are often reluctant to raise questions that might distress older participants, which she suggests might be a form of internalised ageism. On reflection, our need to ask questions related to death and dying in the last round of interviews suggests that we were hesitant to raise them earlier.

Approach to analysis

Face-to face interviews were transcribed verbatim and the transcripts read by the two researchers that had conducted interviews[1]. Emergent themes and questions were discussed with members of the research team and an Advisory Group. At the end of the field work there were 134 transcriptions of interviews of between one and two hours as well as notes from telephone calls and field notes. Every transcript was re-read and marked at key points to add to and develop the *a priori* themes and those identified over the course of the study. Our approach to analysis was to produce frameworks with cross-cutting themes on the vertical axis and individual 'case' accounts on the horizontal (Lewis 2007). The analytic process was informed by that developed by Spencer, Ritchie and O'Connor (2009) involving progression from descriptive to explanatory themes.

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[1] The anonymised transcripts are deposited with the Economic and Social Data Service (ESDS).

To maintain our focus on the research questions, we initially prioritised cross-cutting descriptive themes, identifying eleven: health and illness; significant relationships; home and environment; everyday life and activities; functional health and mobility; treatment and professional support; independence and obtaining help; ageing; the life-course; the future and preparations for the end of life; dignity. Some themes (including health, medication and mobility) were analysed chronologically, focusing on participants' accounts at the time of each interview and exploring changes through the course of the study. However, as Lewis (2007) found, the significance of the different time points was variable and it was necessary to take a more fluid approach. Individual life stories became increasingly important to the thematic analysis. For example, the theme of 'independence' included everyday things participants did now without help, what they needed help with, from whom, how this had come about and how they felt about independence in general. Below is an extract from a single cell in the framework on independence from interviews with Rose, who lived in supported housing where a warden was employed.

> IV3: [line] 437 '*I think a lot is left to yourself ….'* [Warden says]: *"I wish they were all like you"'*. Regrets loss of GP/Nurse home visits. '*You never see anybody now'*. Cost of taxi to surgery. The more independent you try to be, the less help you get offered (IV4:1131). But couldn't change her ways '*Brought up that way'* (IV4:1150 - leopard/spots).

Rose's personal values are inextricably linked with how she was brought up but also with the contemporary cultural value of independence, as implied by the warden's comment. Her account also suggests that if support were provided more routinely her sense of independence would not be compromised. For Rose, it is having to ask that affects her sense of independence. Her account thus reflects the individual, familial, institutional, social and cultural dimensions of independence. It also shows the persistence of continuing themes in later life, even during a period of significant change in circumstances.

Findings

The discussion of findings below highlights the precarious and unstable nature of participants' lives. Frequent and continual changes affected their day-to-day activities, relationships and living arrangements as well as their perceptions of their lives and identities. It focuses on the significance of these changes for individuals and on their relationship with different sources of help and support, which show how dignity and threats to dignity are experienced.

Health maintenance and long-term illness

The long term health trajectory of each participant was rarely smooth, involving periods of crisis and downturn, as well as relief and upturn. Table 2 gives a summary of participants' descriptions of their health and illness over the course of the study.

Table 2 about here

All participants expressed a strong sense of personal responsibility for maintaining health, typical examples being daily walks, crossword puzzles and care over diets.

They also described regular routines they had developed, such as monitoring medication and its side effects, as well as regular appointments for check-ups and tests. At the second interview Peter said:

> *I check my blood pressure because the doctor……. says he wants to get it down to 130/80, which it's pretty well near that now. The medication's working and I also decided to supplement the medication. I bought a book on alternative medicine and found that soya milk brings blood pressure down and so does pomegranate juice.'*

As Bytheway (2001) and others have found, decisions over medication often occupied a lot of time and emotional energy. Of the 28 participants alive at the end of our study, 15 had refused, changed or stopped prescribed medication and another 5 had discussed these possibilities with their doctors. Unpleasant and sometimes embarrassing side-effects, such as sweating, rashes, dizziness, nightmares, sexual impotence and urinary incontinence, influenced their decisions, as did fear of becoming over-dependent on medication. Sometimes a balance had to be struck between the potential future consequences of stopping and the present-day side-effects of taking medication. James commented:

> *'I told [the Parkinson's nurse] that I left the statins off and I said I'd sooner drop dead from a heart attack in a week's time than live another 10 years and end up like a...with more and more...like a cabbage, you know.'*

In addition, decisions about medication were often morally charged. For some, compliance with medication was the 'right thing', because having asked for the doctor's advice they should take it. For others, being a 'pill-taker' signified moral weakness, and medication was best avoided completely or taken in reduced dosages, although it might be accepted grudgingly as a necessary evil. Health services were highly valued in general, although several participants gave examples of health professionals they disliked and recounted stories of neglect when they were in hospital. Some experienced rude and arrogant treatment by doctors, which they found deeply undermining of their dignity.

Precariousness, time and change

The changes in health that had occurred prior to or happened during the study were often described by participants as coming 'out of the blue' and having 'hit me for six' - terminology that portrays a sense of shock and devastation. Some described the onset of ill-health as signifying a major life change or transition, which could be old age itself. Describing the time his knee problem stopped him from getting out, Brian remarked: 'That's when I knew old age was upon me and no mistake'. Corden and Millar (2007) discuss the ways in which past and future time impact on the present. This was clearly evident in our participants' accounts, which were peppered with expressions such as '*I used to'*; *'while I can'; 'still';* and *'as long as…'*

> '*I wish I could walk better, but never mind, I can still go out'* (Jane)
>
> *'Ageing doesn't bother me as long as I can keep going, like.'* (Robert)

Such expressions denote the unstable and contingent nature of their lives, the constant awareness of how different things were now from how they used to be as well as how precarious their current circumstances were as they faced an uncertain future. At the first interview, like many others, Graham concentrated on the here-and-now, commenting that looking towards the future is '*a particularly unhelpful thing to do because you don't know what lies ahead*'. In the third interview, he said: '*The medical men said I must expect things to change a lot' …. 'I know things will not get better it's only a question of how long I go on'*. Although he found the doctors' prognosis distressing, he also described a sense of relief from the constant disappointment that his efforts with exercise had not improved his mobility. At this point, therefore there was a qualitative difference for Graham in the meaning of the 'here and now' because of his changed perception of the future.

The theme of change permeated all participants' accounts but in qualitatively differing ways. Change in health and mobility could signify, for example, loss of social status, loss of a cherished activity or change in a long-standing marital relationship. Change could be sudden or gradual, episodic or ongoing. While it often came out of the blue it could also be the result of decisions and actions to preserve and maintain a way of life as far as possible or to minimise risk. For example, during the study, several participants decided to give up driving. On the positive side, learning new skills, such as using the internet, texting and Skype, enabled participants to maintain their family and social relationships as well as to explore information about their health and medication and follow personal interests.

Change - or the possibility of change - in living arrangements was a major consideration for most participants, particularly those who had lived in their homes for many years. Some agonised over decisions about where to live because, as Degnen (2015) points out, their attachment to home and neighbourhood was deeply significant in terms of their histories and creative activities over the years. They often pointed to home improvements and to articles that had a family history or memorialised a lost partner. Some decided that moving house would be too much trouble at their 'time of life' while others found that, once made, a move could be seen positively in retrospect. Brenda, for example, moved to a care home and found relief from the pressure of living in supported housing, as well as from anxiety about being a burden on her daughter.

Across a range of topics, participants were often eager to explain the rationale behind decisions they made and to explain how, in retrospect, it was the right decision. The process of resolving dilemmas often involved family members, friends or professionals. For example, at the beginning of the study, Lena was pondering whether or not to have a stairlift installed, because her son was anxious she would fall on the stairs. In the second interview she said that the nurse at the falls clinic had similar concerns but Lena was still reluctant. Some years previously, when her late husband was dying, a stairlift had been temporarily installed and Lena dreaded the prospect of a constant reminder of this dreadful time. By the third interview, she had reluctantly agreed to have the stairlift installed, the deciding factor being the potential effect on her son if she were to have a fatal fall, which she had come to accept was highly likely.

The family relationships of participants were also subject to change as a result of their illnesses, and increasing levels of dependency. Most told us how they had come to rely on family members to support them in public, such as in restaurants, public toilets and transport, as well as in diverse ways in private. Participants also described how they reciprocated where they could with, for example, financial help, care of young grandchildren and accommodation for older ones. Some talked about the prospect of family events such as weddings as a reason to stay alive. In response to questions about their preparation for the end of life, many said that they trusted their sons or daughters to make ‘the right decision’ on their behalf and that they had not considered discussing this with their GPs. The importance of family ties was also evident in the accounts of widowed participants, who described how their growing need for support exacerbated the pain of bereavement. A minority of participants had troubled family histories, including long-standing estrangement from sons and daughters, described with bitter regret and fear about the future. During the course of the study, Dorothy left her partner of twenty years and was helped to move by her friends from the day centre into supported housing. She hoped this separation would bring about reconciliation with her children by her first marriage. Jonathan had been estranged from his daughter since his divorce from her mother but in the third interview was overjoyed about their reconciliation. In the fourth interview, he was considering leaving his wife because as he grew physically weaker he felt threatened by her. The highs and lows of family life were therefore a continuing theme but had particular significance because of participants’ advanced age and uncertain future.

Independence: perseverance and asking for help

Unsurprisingly, independence was widely regarded as crucial to dignity but participants' differed in their views about what it meant in practice. It could mean, for example, 'being able to do what you want to do', 'being able to decide for yourself', 'not needing help from anyone' or 'being able to stay in your own home'. Views of independence as an abstract idea often differed from how particular situations were viewed. Peter described himself as '*independent to the point of being daft about it'*, yet also said that he and his wife should have had more help when he was discharged from hospital. Participants' sometimes explained why particular circumstances allowed an exception to their general rule. David, for example, said he had only been in a wheelchair on two occasions '*for a proper reason'*, such as the convenience of his family, because '*I'm not a wheelchair person*'. Such moral justification was clearly important to participants' continuing sense of self and self-respect. Many participants referred to the importance of moral fortitude and determined mental and physical effort in facing up to the impact of their ill-health. The term that several used was '*perseverance*', which encapsulates their active determination to maximise their capacity for self-reliance, drawing on their personal resources to do so. Over the course of the study, however, participants' views of perseverance often altered as they realised they would have to make inevitable adjustments to their changing health and physical abilities.

Participants gave vivid accounts of the giving and receiving of help, including from paid staff as well as from families and friends. The prospect of personal (bodily) care was dreaded by those who did not yet need it but the experience of it was at least less negative than expected and could be quite positive if they liked the carers (see also Coleman, Ivani-Chalian and Robinson , 2015; Grenier 2012). Some said that keeping up standards of personal hygiene was the most important consideration while others regarded personal care as the means by which they achieve their aim of staying at home. Help from a family member sometimes mitigated the negative effects of reliance on paid carers. Harry's wife described how, although it was the carers' job, she would get him up in the morning before they arrived '*to preserve his independence'*.

Cuts to services, such as podiatry, community nursing, libraries and social clubs reduced participants' sources of support but also created uncertainty about their entitlement and anxiety about how they would be regarded if they asked for help. Valerie said that asking for help made her feel she was '*a pest'*, while Norman said *'I think sometimes people think "Oh look at that idle bugger," You know, cos I don't (laughs) … I don't go to work or anything like that, and laying in bed till 9 o'clock in the morning*'. Their sense of self-respect was therefore inextricably linked to the accessibility and availability of services.

Discussion

Small (2007) comments that what matters most about old age is the human being's heightened exposure to contingent harms related to serious ill-health. This study focused on older people's subjective experiences and perceptions of this heightened exposure and considered the lessons for our understanding of dignity. It has underlined the multi-faceted nature of dignity as involving personal identity and self-respect as well as social status (Lloyd et al 2014). Participants' stories of falling, loss of bodily control and mental confusion portrayed vividly the embodied nature of identity as well as the aesthetic aspect of dignity, which can be easily undermined by such experiences. At the same time, participants differed in how they regarded the significance of their experiences and in the reflexive process each went through as they adjusted to change. The diversity of their experiences and views reinforces the importance of subjective perspectives on the lifecourse, and the challenge to standardised, stage-based models (Grenier 2012). Barnes, Taylor and Ward (2013) highlighted older people’s ability to accept themselves as they are, rather than being critical of their inability to meet a standardised measure of independence. This is an important point that resonates with our findings but, as discussed, acceptance involved a continuous process, as there was no stability in participants’ situation ‘as they are’. The weariness that our participants experienced from time to time often arose from the overbearing necessity to manage changing circumstances, with the prospect that tomorrow could well bring a different challenge.

As in the longitudinal case studies by Coleman, Ivani-Chalian and Robinson (2015) individual participants in our study differed considerably in how they adjusted to changes. Emotion played an important role in participants’ decisions about seeking help from service providers, which support the findings of Baxter and Glendinning (2013, 2011). As discussed, decisions about seeking help were also morally charged and it was important for their sense of dignity and self-respect that they felt they were doing the best they could in the circumstances. We concur with the point made by Millar (2007:538) that a QL approach is uniquely suited to understanding how people explain the relationship between their individual choices and actions and the conditions under which they make these. It was striking how much mental and emotional labour was spent by our participants on making decisions and adjustments, each of which was deeply significant to maintaining their sense of self and their dignity (Lloyd et al 2014). Their perseverance can be understood as a continuous reflexive process of exerting mind over matter while also accepting that matter would, in the end, trump mind.

This reflexive process occurred within familial, social and cultural contexts as well as by reference to earlier life-course experiences. The findings, thus, also draw attention to the importance of relationships to dignity. As discussed, families and friends were crucially important to enabling participants to deal with their precarious circumstances and losses, to overcome their fears and maintain a sense of security and belonging. Participants often needed help to find a resolution to the ongoing dilemmas they faced, including those related to their living arrangements, and often it was a family member that provided this. The QL method enabled us to trace not only the flux and change of family life during the study but also the ways in which family histories shaped present-day patterns of help and support and influenced decisions. As Degnen (2015) found, this included those who were absent, also. Widowed participants still considered their late partner’s views when making decisions.

Laceulle and Baars (2014) argue that dominant cultural narratives about ageing as a chronological and biological process have come to shape individual expectations as well as obscuring ageing’s socially constituted nature. This point is well illustrated by the discussion of participants’ unstable views of independence. Within their lifetime, there has been a significant cultural shift as post-war values of shared responsibility for welfare have declined as individualistic values of personal responsibility have been ascendant. Our participants were vulnerable, therefore, not only because of their health problems but also because of their social position as older people in need of help. Jolanki (2009:271) argues that older people ‘struggle within available discourses of justification in order to retain their human standing’. In our study, the longitudinal approach has provided insight into the nature of this struggle as participants came to terms with their increasing need in the context of diminishing sources of public help and diminished entitlement as citizens. It has also shed light on the potential of both formal services and family help to maintain older people’s dignity when help was offered without participants having to ask for it.

Conclusion

This article has discussed the value of a QL methodology in research into dignity in later life in the context of serious ill-health. It has placed strong emphasis on understanding older people’s perspectives on this turbulent time. The findings highlight the scale of changes they experienced and the efforts they made to persevere. They challenge the commonly held but simplistic idea that the dignity of older people in poor health is in the hands of those who provide support and care services. The complex and fluid nature of dignity is underlined by the longitudinal approach. The QL methodology ideally suited to exploring the complex relationship between continuity and change in later life and to drawing out the links between the individual and the familial, cultural and social contexts that shape the conditions in which people age.

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Table 1 Selected participant characteristics at Interview 1

Pseudonym	Sex	Age	Marital status	Previous occupation	Health (own description)
Henry	M	90	M	Firefighter	Skin cancer,
George	M	87	M	Firefighter	Bowel cancer
Edward	M	85	M	Upholsterer	Falls, fractured ribs, blood clot, irregular heartbeat, gout
Adrian	M	81	M	HGV driver	Non-Hodgkins lymphoma
Jonathan	M	85	M	Own business franchise	Heart triple bypass, knee injury, allergy to 1 medication
Lena	F	80	W	Comptometer, wages clerk	Emphysema, arthritis ,lost use of arm, leg ulcer, sleep problems
Andrew	M	80	D	Company director	Cancer, arthritis, hip replacement (awaiting second)
James	M	82	S	Coachbuilder, factory worker	Parkinson’s, diverticulitis, IBS, colostomy, allergy to 1 medication
Alice	F	80	D	Secretarial, PA, sales coordinator	Mastectomy (breast cancer), low energy
David	M	84	M	Teacher	Diabetes, leg cramps, chest pains, triple bypass surgery.
Brenda	F	83	W	Factory worker	Diabetes, osteoporosis, angina, triple bypass, hip replaced. Registered blind
Graham	M	78	M	Lawyer	Stroke
Jane	F	75	M	International conference administrator	Sodium deficiency, irregular heartbeat, asthma, broken ankle
Michael	M	84	M	Careers advisor	Ankylosing spondylitis, fall, pneumonia, eye problems
Brian	M	89	S	Army office, writer	Painful knee, accidental injuries
Rose	F	84	W	School clerical, shop assistant	Stroke, diabetes, problems with feet
Margaret	F	82	M	Manager dry-cleaning chain	Stroke
Peter	M	78	M	Mechanical engineer for council	Cancer of the colon, mini-stroke, polymyositis
Stephen	M	83	W	Army, park ranger, geological surveyor	Stroke, cataracts, hernia

Samuel	M	82	M	Own business	Skin cancer, detached retina
Frederick	M	81	CP	Company rep	Heart problems, diabetes, arthritis
Doreen	F	80	M	Factory machinist	Lymphoma, cancer of womb and bowel, cataracts, vertigo, diabetes
Robert	M	83	M	Painter and decorator, factory worker	Arthritis, knee replacement, broken wrist, hoarseness under investigation
Daniel	M	83	M	Post office telecom line manager	Arthritis, funny turns – fainting, ECG.
Norman	M	88	W	Miner	Emphysema, high blood pressure, deafness, 2 knee replacements,
Harry	M	90	M	Business manager (drapery)	Heart failure, angina, colostomy, deafness, cataracts, carpal tunnel, gall-bladder removed
Howard	M	83	W	Photographer, insurance agent.	Aortic aneurism, macular degeneration, hernia, painful feet
May	F	87	W	Lace market, laundry, office and factory worker	Arthritis, low sodium, painful legs
Phillip	M	88	M	Civil servant	Abdominal pain, cataracts removed
Ruth	F	88	W	Catering, post office TV licences.	Parkinson’s, cramps, thyroid problem, knee replacement
Dorothy	F	75	M	Hospital drugs dispenser	Osteoporosis, psoriasis, DVT, aortic aneurisms (2), lichen planus
Valerie	F	70	D	Factory worker, care worker	Severe anxiety, depression, asthma
Elizabeth	F	70	W	Shop worker	Tumour behind eye, arthritis, high BP, high cholesterol.
Irene	F	88	W	Factory, shop, office work	Fall, poor eyesight, osteoporosis, painful shoulders

M = married, W = widowed, D = divorced, CP = civil partnership

Table 2: Changes experienced over the course of the study

Given name	**Health/illness and significant changes (drawn from participants' accounts)**
Henry	Overall slowing down
George	Died before second interview
Edward	Increased mobility problems, prostate cancer diagnosis, jaundice, stent inserted, 2 falls
Adrian	Broken shoulder now healing. Lymphoma in remission
Jonathan	Increasing mobility problems, depression, extreme tiredness
Lena	Deteriorating mobility and use of arm but attended falls clinic and feels more stable
Andrew	Increased pain, high blood pressure prevents surgery, endoscopy for gut problem.
James	Deteriorating Parkinson's, Baker's cyst, deteriorating eyesight, heart problems
Alice	Broken arm but recovered. Loss of energy
David	Becoming weaker and weaker. Several falls
Brenda	Hospitalised for heart attack. Moved to nursing home
Graham	Began using wheelchair, problems with speech and concentration
Jane	Relapses of sodium problem, emergency hospital admission for heart, fall, cataracts removed. 'Going downhill slowly'
Michael	Hospitalised then moved to sheltered housing
Brian	Moved to nursing home by second interview. Died before fourth interview
Rose	Mental health problems linked to bereavement, eyesight and mobility deteriorating, several falls, stroke (3 yrs prior to study) and diabetes.
Margaret	Cataracts. Mental health problems linked to multiple bereavements
Peter	Slowing down, less agile and mobile
Stephen	Decline in mobility, pain in shoulder but cancelled surgery as problems with wounds healing.
Samuel	Stiffness in joints, 'hard to get up every morning'.
Frederick	Mobility very impaired, permanent pain, cataracts
Doreen	Non-diagnosed problem with bleeding from bowel, weight loss, weakening, poor mobility.
Robert	Stomach cancer already spread. Refused chemotherapy and died before fourth interview
Daniel	Falls, diagnosis of low blood pressure. Kidney failure as result of medication
Norman	Worsening arthritic pain in knee but emphysema preventing surgery.
Harry	Heart failure. On oxygen for 18 months. Died before fourth interview
Howard	Slowing down, more painful feet, macular degeneration
May	Deterioration in walking ability, increased pain. Low in spirits.
Phillip	Died shortly after his wife moved to residential care, before third interview.
Ruth	Knee replacement, back on her feet and reasonably stable
Dorothy	Deteriorating mobility. Steroids for lichen planus, psoriasis. Left her partner and moved to sheltered housing
Valerie	Pacemaker fitted, surgery for gallstones, breathlessness. Hospitalised

	3 months (mental health problems)
Elizabeth	Continuing heart problems and poor mobility. Unable to go out independently. Great anxiety about her son’s mental health
Irene	Mobility deteriorated. Infection following fall. Now unable to go out independently.