

The loss: Conceptualising biographical experiences of disability, social isolation and emotional loneliness in North-East England

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Abstract: Research into experiences of social isolation and loneliness has predominantly focused on older adults, those post-retirement, as a significant at-risk group. Similarly, research exploring disability and loneliness has been associated with old age and conceptualised as an inevitable outcome of 'failing' health. This study seeks to conceptualise experiences of disability from a wider age group to understand if occurrences of social isolation and loneliness are commonplace. Fifteen qualitative biographical narrative interviews were completed by a Community Research Team, including 7 males and 8 females aged 32–89. A Disability Studies approach was applied to identify significant pathways from isolation into emotional loneliness, experienced by participants; fourteen of whom were affected by disability issues. Key risk factors were identified relating to disabled participants' experiences of 'loss'. Loss was associated with 'loss of ability', 'loss due to bereavement', 'loss of social connectivity' and 'loss of self-confidence'. Participants connected life events concerning loss with spending time alone, *leading to* feelings of emotional loneliness. The findings illustrate key risk factors in being alone during evenings and weekends, periods where disabled participants were most likely to experience subjective feelings of emotional loneliness.

Keywords: disability; social isolation; alone-ness; emotional loneliness; biographical narrative; loss; bereavement; multi-agency working

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Introduction

This article presents research findings from a qualitative study to conceptualise how disabled people experience social isolation and feelings of emotional loneliness. It commences by discussing how previous research has linked older-age (post-retirement) with disability, predominantly defined through a pathological explanation, to conceptualise risk factors associated with experiences of loneliness and isolation. Thus, the aim of this study is to move beyond these individualistic explanations towards a structural analysis of disability, social exclusion and pathways into emotional loneliness. The findings are from the first, exploratory stage of a two-stage, mixed-methods community research project into social isolation and loneliness. The qualitative data is analysed from biographical narratives of fifteen individuals who agreed to discuss social isolation and loneliness within their communities; fourteen of whom identified as experiencing disability issues. The study was conducted in North-East England to examine the extent to which social isolation and loneliness affects people living in Sunderland.

A biographical narrative approach was undertaken to enable each participant to present a narrative based on their own lived experience (Wengraf, 2001). Following the data collection, a thematic analysis using a grounded theory approach was completed, and through coding (Patton, 2002; Birks and Mills, 2015; Flynn and McDermott, 2016), key themes were identified: 'loss', and increasing alienation during '*evenings and weekends*'. Narratives from interviews were used to demonstrate differing responses to life events of those who identified as experiencing social isolation and/or loneliness. Taking a Disability Studies perspective, these findings illustrate the need for a preventative and proactive multi-agency response to those dealing with social isolation and loneliness to reduce their risk and impact.

Understanding social isolation and loneliness

Over recent years UK government policy has begun to focus on understanding social isolation and loneliness in adults, specifically older and younger people (Prime Minister's Office, 2018). Yet the concept of loneliness came to the attention of public policy much earlier (Sheldon, 1948; Townsend, 1959). Sheldon (1948) identified 8% of people as substantially lonely and 13.7% as experiencing periods of loneliness. His findings illustrated how older people were most at risk of experiencing loneliness (Sheldon, 1948; Victor and Bowling, 2012). Townsend (1959) expanded on these findings, concluding that it was family and community support that had the potential to protect older adults from experiencing loneliness. More recently, these have been theoretically expanded upon by scholars such as Wilkinson (1998), Kawachi (1999) and Halpern (2005) with reference to health inequalities and social capital. They illustrate associations linking structural

inequalities concerning poor education, employment, housing and the experience of social deprivation, with that of social capital; defined as reduced levels of social participation, quality of individual relationships and the weakening of social networks. From their perspective social capital is conceptualised as a social good resulting in social cohesion and reducing an individual's risk factors to poor health and wellbeing. However, just as there are benefits when individuals achieve social cohesion, there is also a risk to their wellbeing due to a lack of social capital through the weakening of these social bonds.

Recent research that has specifically examined the experiences of loneliness and wellbeing have tended to remain focused on experiences of older adults, where poverty and disability become secondary factors to old age (Bennett and Victor, 2012; Tanskanen and Antilla, 2016; Shvedko et al., 2018). Interestingly, these studies also illustrate some methodological issues emerging when investigating loneliness (Tanskanen and Antilla, 2016). These previous studies measured loneliness through a staged-approach where approximately 7% to 9% of the UK population experienced significant periods of loneliness; whereas a larger population experienced episodic periods of loneliness, increasing from 14% in 1948 to 39% in 2014 (Sheldon, 1948; Townsend, 1959; Bennett and Victor, 2012; Tanskanen and Antilla, 2016; Shvedko et al., 2018). This staged-approach has been criticised, and recent research has detached the notion of loneliness from social isolation. Tanskanen and Antilla's (2016) research suggests a clear separation between these two concepts:

[social isolation refers to s]mall social networks, infrequent social contacts, absence of confidante connections, living alone, and lack of participation in social activities are criteria that have been used to define social isolation;

[emotional l]oneliness is a subjective feeling of being without the type of relationships one desires. It may also describe a deficit between the actual and desired quality and quantity of social engagement. (p.2042)

These two concepts are intertwined, as social isolation can lead to feelings of emotional loneliness, so whilst the concepts of social isolation and emotional loneliness are separate, they are nevertheless interconnected (Tanskanen and Antilla, 2016).

The impact of loneliness

Understanding the experience of social isolation and loneliness is beneficial to understanding people's subjective feelings of loneliness. As Townsend (1959) identified, social relations are important for the health and wellbeing of individuals, and therefore research looks to understand how social isolation and loneliness

can impact negatively. Shvedko *et al.*'s (2018) study refers to the negative impact of social isolation and loneliness on mental health, whilst Steptoe *et al.* (2013) and Holt-Lunstad *et al.* (2015) found loneliness can have a significant impact on mortality rates in both men and women, with people experiencing social isolation and loneliness much more likely to be subject to hospital admissions (Longman *et al.*, 2013). Kearns *et al.* (2014) found that those living alone, especially with chronic health conditions, were much more at risk of feelings of loneliness. Whilst a health impact is evident, this does not mean social isolation and loneliness are exclusively a healthcare problem. Instead, this is a social problem as, to prevent health issues emerging, focus is needed on the reasons why people follow pathways into social isolation and loneliness, which can lead to medical deterioration. Holt-Lunstad and Smith (2016) suggest it is imperative that, in addition to understanding their health needs, each person must be understood as a whole person; understanding how they experience social isolation and loneliness and how they affect their overall wellbeing.

Research by Bennett and Victor (2012) found the permanent absence of loved ones due to bereavement engendered feelings of emotional loneliness in their participants. They reported loss of confidence and magnified feelings of emotional loneliness during evenings and weekends. However, their research focused specifically on widowed older people. Similarly, Shvedko *et al.* (2018) referred to older people as most susceptible to negative impacts of social isolation and loneliness. Yet, Tanskanen and Antilla (2016) highlight concerns that research has tended to focus on adults over 50; to fully understand the experiences and risks of social isolation and loneliness, research must focus on a broader age-range. Generally, research into social isolation and loneliness has taken a psychological and quantitative perspective, correlating experiences with demographics or relationship status. However, there is value in understanding experiences from a qualitative perspective so that lived experiences can be observed.

Disability, social isolation and loneliness

As illustrated, previous research focused on old-age as the main risk factor for social isolation and/or loneliness (Paul *et al.*, 2006; Rokach *et al.*, 2006; Valtora *et al.*, 2016), and disability is frequently discussed as a health problem (Longman *et al.*, 2013; Holt-Lunstad and Smith, 2016). Disability is thus represented as a common factor of ageing, and is pathologised and interpreted from an individualistic perspective, where old-age is directly linked to 'poor' health (Paul *et al.*, 2006; Rokach *et al.*, 2006; Longman *et al.*, 2013; Holt-Lunstad and Smith, 2016; Valtora *et al.*, 2016). This correlation is commonly explained as the key factor leaving certain individuals vulnerable to experiencing social isolation, resulting in feelings of loneliness (Paul *et al.*, 2006; Rokach *et al.*, 2006). Central to this biomedical interpretation is that,

as the body ages, it struggles to interact in the same way as its younger incarnation. Thus, the impaired body is used to explain disabled people's reduced contact with family/friends or increased experiences of being 'housebound' (Paul *et al.*, 2006).

From this perspective, loneliness is a public health issue directly accounting for disabled people's experience of social isolation (Valtora *et al.*, 2016). An example of this biomedical interpretation is seen in research by Paul *et al.* (2006) into experiences of loneliness in older disabled people who were also experiencing mental distress ($N = 999$). They suggested physical impairment, mental distress and loneliness are interconnected, and thus loneliness occurs because of changes in a person's health status due to ageing; 'illness and disability may limit social interaction and foster the feeling of loneliness, which seems particularly likely during old age' (Paul *et al.*, 2006, p.224). In a similar study, Rokach *et al.* (2006) concluded that disabled people's negative self-perception of their physical characteristics naturally leads to 'self-alienation'.

These dominant biomedical interpretations, associating old-age with social isolation and loneliness, seldom engage in any structural analysis of disability. Yet, within the field of Disability Studies social problems and experiences of social inequalities are explained as resulting from structural disabling barriers (Oliver, 1996), where disabled people are an excluded minority, and their experiences can often result in social exclusion, alienation and isolation (Oliver, 1996; Barnes, 2012). It should be noted that Disability Studies has been traditionally defined by the Social Model of Disability, where disability is conceptualized as emerging from cultural, social and economic structural barriers which exclude disabled people. This perspective directly critiques the biomedical model as a system of social exclusion or oppression, which individualises the social problems experienced by disabled people (Barnes 2012). This can be observed in the work of Mike Oliver who outlines the social model as:

Disability: a disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have... impairments and thus excludes them from the mainstream of social activities (Oliver, 2009, p. 42)

From this perspective, the problems that disabled people experience are not due to functional limitation but due to environmental factors that prevent people, with a range of impairments, from fully participating in social life. Interestingly, very few Disability Studies research has specifically focused on the relationship between disability and loneliness (Macdonald and Deacon, 2019), yet numerous references to social isolation and loneliness are found within studies on housing and community care (Chappell, 1994; Taylor, 1999; Forrester-Jones *et al.*, 2002; Macdonald *et al.*, 2018b).

An earlier example of this is Chappell's (1994) investigation into the connection between intensity of personal relationships and quality-of-life for people with

learning disabilities. She suggested structural factors (stigmatisation and limited economic resources) result in many people with learning disabilities becoming socially isolated. Community integration programs, after deinstitutionalisation, have failed to support disabled people to build strong friendships within their communities. Chappell (1994) illustrated that while many individuals attended daily activities such as day centres, friendships and relationships formed within those spaces were not supported outside those institutional settings. This often resulted in experiences of social isolation, not due to an impairment effect limiting development of friendships, but because many people with learning disabilities have little control over their personal lives and social networks (Chappell, 1994).

Similar findings emerged from the work of Forrester-Jones *et al.* (2002) examining the living conditions of individuals with learning disabilities or significant mental health issues ($N = 298$). They examined the lived experiences of people who had previously lived in a hospital environment but had been rehoused within the community due to deinstitutionalisation in the UK (Forrester-Jones *et al.*, 2002). A key finding was that these individuals had very little control over their lives and were often housed with individuals who they found difficult, bullying or abusive. Although many of these individuals had contact with numerous people living in close proximity to them, many reported experiencing loneliness on a daily basis. Likewise, Macdonald *et al.* (2018a), examining the experiences of service users with severe mental health issues, reported a lack of interaction and friendship ties between service users within their residential care homes. Furthermore, the study indicated very few service users living in those environments were visited by family/friends. The authors suggest that although service users could leave their residential home at any time, very few took up this opportunity.

A Disability Studies perspective reconceptualises experiences of loneliness from a pathological problem, where disabled people struggle to live independently due to their impairments, to a social problem, caused by removal of services and support. Although social isolation and loneliness is experienced at a personal level, the causes are often at a social level, particularly through lack of services. Within the Findings section this article will present a qualitative analysis of the biographical experiences of participants. Thus, the article applies a barrier-based approach to understanding structural aspects of social isolation and loneliness experienced by disabled people.

Methodology

This project applies a mixed-method approach grounded in a post-positivist perspective (Macdonald and Deacon, 2019). The authors propose that to explore the experiences of disabled people, initially qualitative research should be conducted,

to determine people's lived experiences, followed by quantitative research relating those findings to a larger population. This paper therefore presents findings from the first stage – exploratory qualitative research to conceptualise people's experiences of social isolation and loneliness. This was a collaborative project involving health, social work and social care practitioners. The health implications of social isolation and loneliness were the primary motive for considering people's experiences, to present a community-focused, multi-agency understanding of social isolation and loneliness and make recommendations for future multi-agency practice. A purposeful sample was sought to access those living in Sunderland who were already accessing some form of community service. Service user groups and locations were identified based on the initial literature review which recognised spaces where loneliness could occur. This study was funded by Sunderland City Council to improve and develop effective services within the district. Although the article is qualitative, it was decided that the team would develop a methodology that would incorporate voices of service users, not just within the qualitative stage, but also within the quantitative design stage (Anon, 2018a; 2018b).

To achieve this, a Community Research Group was established within the local area in partnership with a senior public health professional from Sunderland City Council. Hence, the local authority advertised for volunteers from within the community and from health and social care practice to join the University team. Volunteers committed time to engage with research training and become active researchers for the project. From the 10 volunteers, four were practitioners in health promotion or social care, and six were lay volunteers from a range of socio-economic backgrounds, ethnic-minority groups, and the disabled community. Four individuals self-identified as disabled, including physical, sensory and specific learning impairments, and one person identified as having a significant mental health issue. Volunteers were trained in research methods designed to equip them with the relevant ethical, theoretical, qualitative and quantitative skills (Wengraf, 2001; De Vaus, 2014; Hesse-Biber and Johnson, 2015) to conduct a relatively large-scale study ($N = 680$).

The project was conducted over one year, from September 2016 to September 2017. The first stage was the completion of fifteen qualitative biographical interviews (Wengraf, 2001). In order to understand how different people express and understand their experiences, the opportunity was sought to gather their narratives. As the first step in a larger-scale research process, qualitative data was collected from service users who identified or disassociated with experiences of social isolation and/or loneliness. Fifteen people were thus interviewed and Table 1 lists each participant's pseudonym, gender and age. The ages of participants ranged from 32 to 89 as the team sought to perceive how loneliness and isolation effects people across their lives, to move away from previous studies suggesting that it is a particular issue with regard to older age (Bennett and Victor, 2012; Tanskanen and Antilla, 2016; Shvedko et al., 2018). Of these participants, fourteen were identified

as experiencing issues relating to disability; only participant 1, Ann, did not.

Table 1: The participants

| Participant | Gender | Age | Pseudonym |
|-------------|--------|-----|-------------|
| 1 | Female | 32 | Ann |
| 2 | Female | 36 | Bella |
| 3 | Male | 62 | Christopher |
| 4 | Male | 59 | Dan |
| 5 | Male | 47 | Ezekiel |
| 6 | Male | 67 | Frank |
| 7 | Female | 62 | Georgina |
| 8 | Female | 64 | Hannah |
| 9 | Male | 45 | Ian |
| 10 | Male | 53 | John |
| 11 | Female | 52 | Kate |
| 12 | Female | 82 | Lynn |
| 13 | Female | 52 | Maureen |
| 14 | Female | 89 | Nora |
| 15 | Male | 62 | Oliver |

To begin the data collection process service users were asked the following question: ‘*Can you please tell me your life story, with all the events and experiences which you feel are relevant, concerning your life? I will listen without interrupting you*’ (Wengraf, 2001, p.119). Participant responses to this question ranged from 2–56 minutes. Following this, each interviewer analysed the transcript to devise a list of semi-structured questions based entirely on each participant’s life story (Wengraf, 2001), designed to explore and expand their biographical narratives. The final interview involved further questions relating to the literature review, enabling researchers to explore how this linked to the participants’ views and experiences. In the final stage of analysis, once the initial codes were completed to determine which made the most analytical sense, the Community Research Team started with initial coding then moved to focused coding, where some codes were dropped (Strauss and Corbin, 1990). It was following the focused coding stage that key themes were identified used to underpin the quantitative stage of the project (Anon, 2018a; 2018b), to test the qualitative themes across a broader participant-base (Macdonald and Deacon, 2019). Following this, axial coding was completed by the lead author of this paper, where the focused codes were re-explored and evaluated to add to the emerging theoretical conclusions (Strauss and Corbin, 1990). As Charmaz (2006) advises, initial coding fragments the data, and axial coding then works to reassemble the data, but into the researcher’s view.

The data findings that will follow emerged from four significant themes: ‘*Loss of*

Ability, *Loss due to Bereavement*, *Loss of Social Connectivity* and *Loss of Confidence*. A key risk factor was also identified concerning *evenings and weekends*. The ages of participants are included in the Findings section to indicate the continuum of experiences across the age-range of adults concerning loneliness and isolation. These themes are explored with reference to participants' stories in the Findings section of this article, which are purposefully broad to indicate exploratory implications of knowledge from people's narratives. A Disability Studies perspective was employed to emphasise the importance of enabling interview participants to share their own experiences. Furthermore, the authors applied a critical realist interpretive approach within the data analysis (Shakespeare, 2015), and the team also used the standard social model definition of 'disability' referring to structural barriers, and 'impairment' as biological/neurological variation, to conceptualise disability (Oliver, 2009). This is the third paper presenting the qualitative data results and which can be used in conjunction with our two quantitative articles (Anon, 2018a; 2018b).

'Loss' due to dis/ability

The central theme emerging from the biographical narratives of participants was the notion of 'loss'. Loss was used in conjunction with 'loss of ability' (that is, disability), 'loss due to bereavement' (for example, parent, grandparent, sibling, child, partner), 'loss of social connectivity' (breakdown in relationships, unemployment, retirement and the like) and 'loss of self-confidence'. These experiences of loss intersect and can have significant life course connotations, which for participants in this study resulted in experiences of emotional loneliness. When exploring loss concerning experiences of disability, numerous participants describe this in association with the concept of 'loss of ability'.

On the whole, fourteen participants reported associations between experiences of disability or mental health having significantly affected their life-course and resulted in experiences of emotional loneliness. Within the issues reported by this group: five were concerning physical impairment; one was regarding a sensory impairment; six related to mental health difficulties; and two were affected by the deterioration of a loved-one's wellbeing due to dementia. For the participants with physical or sensory impairments, the loss of 'ability' was often associated with employment or leisure pursuits. This is illustrated by John (53) who became a disabled person due to a head injury which not only resulted in unemployment but also led to alienation due to loss of friendship groups associated with sport.

As a result of the head injury I couldn't play football really, I couldn't head the ball... I couldn't meet with the people I used to play with which was hard. John (53)

For John the loss of these friends resulted in substantial experiences of loneliness.

Although John reports having to make new friends after this incident he also describes a lack of emotional connection to this new group of peers. For John the experience of becoming a disabled person led to a weakening of his friendship groups due to his inability to engage in his *chosen* leisure activities. John later reports that although he would not describe himself as socially isolated, as he has some degree of contact with people within his area, it is his loss of friendship which weakens his emotional connections to his peer groups. For John, becoming a disabled person has led him to discuss periods of loneliness throughout his biographical narrative.

It should be noted that not all participants with physical impairments reported loss of contact with family and/or friends, but it did affect their relations. For Nora (89), discussing the emotional impact of losing her hearing in older age, the key problem arose concerning family communication. Nora states that although she does not consider herself socially isolated, as she has strong ties with family and friends, she experiences loneliness due to her inability to communicate with them. As Nora states:

There was the loneliness that deafness brings because everyone else is laughing at something and you don't know what they're laughing at or erm, somebody says to you 'You know we told you about so and so or it was announced' and you say 'I'm sorry I didn't hear or I didn't even know about it' That is living in a sort of side-line bubble. Nora (89)

Similar experiences emerged for participants reporting significant mental health issues. For these six participants, all reported loss of friendship groups, and on occasion family members. Furthermore, three participants reported experiencing unemployment due to their impairment. Experiences of mental health seemed to have an isolating effect on participants as they became more reluctant to engage with, and interact within, their communities. This was particularly the case when a participant was experiencing a mental health crisis. In Ezekiel's (47) narrative, mental illness contributed to experiences of unemployment but did not lead to loss of social connectivity with family members. Thus Ezekiel describes having important contact with members of his family. For this participant loneliness only affected his life during the evening when he was not in contact with them. Ezekiel reports:

I find my life now really lonely even though I have got my family round us ... I see my sister quite often... and I pop round for a coffee and see my son sometimes... and most of the time I am round my mam's... but on a night time I get really lonely my mind runs away with itself on a night time errr ... I do find my life really lonely... Ezekiel (47)

For Ezekiel the experience of loneliness only occurs during evenings when he is not in contact with his family. Unfortunately it is during these periods when Ezekiel reports he is most at risk of loneliness which has a significant negative impact on

his mental health and emotional wellbeing. Within this narrative we can observe a relationship between specific periods of loneliness and the deterioration of Ezekiel's mental health, which is somewhat representative of the wider disabled group in this study.

Interestingly, two of our participants, although did not identify as a disabled person, also suggested that they were significantly affected by their loved-one's experience of dementia. For Christopher (62) the experience of his wife had significantly transformed his own relationship with his community. Christopher reported the deterioration of his wife's health resulting in her moving into a care home. In Christopher's narrative we see a lack of services during the early onset of dementia resulting in his and his wife's loss of social connectivity. His responsibility of care to his wife thus alienated him from his wider community. Now his wife has been moved to a care home, Christopher reports that his daily activities are now situated around visiting times. Although he has a relationship with his wife and care staff, he has very little interaction with other peer groups or family members. Hence, Christopher's experiences of his wife's mental capacity seem to have resulted in him becoming increasingly lonely and socially isolated.

'Loss due to bereavement'

Similar to the classic work of Peter Townsend (1959), participants in this study also referred to various experiences of loss, particularly concerning bereavement. Eight participants referred to bereavement (past or recent) as a significant risk factor to pathways into loneliness and social isolation. The ways in which participants began their narratives with stories of bereavement are illustrated by Hannah (64) and Lynn (82). Although they would fit into the classic profile presented in previous studies on older people (Townsend, 1959; Victor and Bowling, 2012), it should be noted their experiences of 'loss through bereavement' took place in childhood (for Hannah) or early middle age (for Lynn). Within Hannah's narrative, the death of her mother in childhood had a significant impact on her and left her vulnerable to experiences of loneliness in later life.

My life story started... once my Mum died when I was ten years old... everything changed in my life. Hannah (64)

Similarly, from Lynn's perspective it was the loss of her husband at 38 which led to a significant pathway into loneliness and isolation in her narrative.

...Events in my life ... well the most horrendous one my husband died when I was 38. Lynn (82)

Bereavements were experienced at different times, and some were natural and some traumatic. For example, three participants, Dan (59), Lynn (82) and Maureen (52), all experienced the loss of a partner due to cancer, whereas for Nora it was the loss of her son due to his suicide. Others referred to loss in childhood that was still a significant part of their story, for example, Ann (32) lost her grandparents, Ian (45) his parents, and Nora (89) her sibling as a baby. The significance of these events is given by the participants themselves, and this suggests that feelings of loss and loneliness are still being carried by the participants years later and remain a significant part of their narratives. As suggested by Walker and Shaffer (2007), if not given attention, grief can still be felt later in life, even years after the event. Interestingly, what seems to emerge from the qualitative data is that loss through bereavement was a significant risk factor which led to a weakening in social connectivity and, for some, was a significant pathway into experiencing loneliness and/or isolation.

Conceptualising ‘loss of social connectivity’

What seems to be significant about participants’ experiences of loss is the connection in their stories between ‘loss’ and *spending time alone*. Whilst being lonely and being alone are different (Tanskanen and Antilla, 2016), from the experiences shared in the biographical narratives there was a significant relationship between the two issues. Participants connected their story of loss with time spent alone and loneliness, and it was in the way they talked about being alone that the relationship with loneliness was visible. Hannah referred to the loss of her mother and her grandmother, stating that she lived alone but was happy with that after a number of difficult previous relationships. However, she identified that without her work she gets lonely:

I live on me own ... I'm happy ... it could get lonely ... but I throw meself into working
Hannah (64)

She indicated a number of activities she was involved in to keep herself busy, so as not to be left alone. Ian (45), suggested he was not lonely but that he did not have ‘*proper friends*’, just people he saw when he went to a café. He also acknowledged that he spends most of his time alone and tries to keep ‘*busy*’, as his narrative below indicates:

I don't really, just the people I see in the café... I've got plenty of hobbies and interests to keep us busy so I dare say if you're saying someone's lonely I dare say you would say that I am, a bit lonely. It's just that I'm on my own, shopping on me own, I go home alone and all that side of things... I usually get up have a cup of tea, breakfast and then I go out for an hour, you

know just to get out the flat. Ian (45)

Later in the interview he did refer to himself as 'lonely', but in the data, many disabled participants did not explicitly refer to being alone or being lonely; there was, however, indication in their responses that they were employing strategies to avoid (alleviate or distract, Ryckeboosch-Dayez *et al.*, 2016) feelings of loneliness.

'Loss of confidence'

The outcome of spending time alone reported by participants was loss of confidence – many related this to the question of how to re-engage with society once they had lost some contact. Even if this choice was not theirs and it happened around them, they then began to lose confidence in being able to re-engage; this was also found by Bennett and Victor (2012). Frank (67) talked of having lost confidence in his ability to engage with others, which increased his feelings of loneliness. He talked of how a flight of stairs could be problematic for him due to his disability, and so this led to him finding it harder to engage with activities; he also referred to being let down because people forgot about him, for example, the university course that was '*promised*', he said he felt '*pushed aside all the time*'. Frank went on to suggest that the depression and loneliness he felt meant his motivation had gone, which led to increased fear of going out.

It's just so lonely and I feel incapable of doing anything, it sometimes scares me to go out down into town because you don't know what peoples going to be like. Frank (67)

Ian (45) indicated it was up to the individual to make the effort to go out and meet people to address their loneliness, to find things to do. This was similar to other participants' views, and those who referred to experiencing mental health difficulties, indicating that significant loss of confidence and loss of motivation can lead to the increased difficulty these people have, and how feelings of loneliness can increase and become magnified. Kate (52) referred to anxiety and mental health impacting on her confidence, and that this stopped her from feeling able to go out into social situations. Living alone appeared to magnify feelings of loneliness for those already feeling lonely or social isolated. Some appeared to do everything they could to keep busy, to keep out of the house; whereas others, such as Kate (52), recognised the loneliness of actually being alone.

I think living alone is a lonely life, it's erm, you know you wake up in the morning and there's no one there. You know, you go out, you come back there's no one there. You go to bed there's no one there and erm, yeah I think in terms of because I'm not working I don't really see anybody to be honest, apart from when I go to me volunteer job, and that's not every week

because of the way, sometimes I find it hard to go out the house so erm, yeah, just lonely. I feel a bit cut off. Kate (52)

The significance of evenings and weekends

Within disabled participants' narratives, it became evident that some people were spending increasing amounts of time at home alone and away from others, especially during evenings and weekends. As Christopher (62) shared his story, it became clear he was out of the house almost every day at different support groups (he identified the loss of his wife following her Alzheimer's diagnosis). What was pertinent was that he did not identify this as a 'social life'. He referred to how much of his time was taken up developing understanding of the impact of his wife's disability, including what financial help was available. Whilst Christopher identified his *knowledge* in dealing with his wife's dementia and the impact on himself, what was significantly missing was that he did not refer to time spent purely on his own hobbies or interests. He referred to his active life as '*all of these things are necessary for to combat loneliness*'. This was similar to Hannah's (64) suggestion that she needed to go out to keep busy, although Christopher specifically identified as lonely and Hannah did not – yet their stories appear similar.

Several participants discussed how they had in fact stopped asking people to come to see them as they felt they were a burden, and therefore spent increasing time alone at home, and instead referred to using their television for company (Bella (36) and Christopher (62)). In their research, Jacobson *et al.* (2017) identified the positive impact *perceived emotional social support* could have on people and how this could alleviate progression towards depression. Those in the study who had stopped engaging with people socially in this way could arguably be at increased risk of escalating depressive symptoms due to this disengagement with emotional social support. It became evident, as the data analysis progressed, that evenings and weekends were particularly difficult for disabled people who lived alone and were experiencing feelings of emotional loneliness. Participants who did go out talked of activities being relatively easy to find during the day, to distract the mind, but during evenings or weekends there was more awareness of being alone and feeling lonely. They referred to how they stopped going to events if they felt they would be a burden, or if they would feel anxious, or if the weather was a problem. Several reported that the more time they spent at home the less confident they felt about going out.

I'm often sitting in the house on a weekend and it's a lovely day like today and I want to go for a walk but I end up going on my own you know so it's like trekking around with no purpose really just for the sake of going for a walk so ... Maureen (52)

Bella (36) identified that experiencing difficulties associated with disability meant going out of the house became more challenging:

You can't get ready quick, you can't just jump in the car you're relying on other people which probably does... indirectly impact. (Bella 36)

Bennett and Victor (2012) also identified this difficulty for their research participants, whereby *being alone* led to feelings of loneliness. This appeared particularly palpable for participants when the act of being alone occurred in evenings or at weekends; the emotional relevance of being in the house alone when others are perceived to be socialising. This is indicative of disabled people's awareness of the impact that being in the house alone at evenings and weekends can have on their subjective feelings of emotional loneliness; where the option to go out or see people appears, to them, not to exist. They become much more aware of their loneliness, even if others they know are *not* out socialising; it was in fact the *apparition* of others socialising that increased feelings of loneliness. One reason behind this, which could be helpful in considering community resources, was that participants referred to how weekends require people to be more proactive, to make arrangements to see others rather than having prearranged clubs, which are usually weekday activities. Combining this with the issue of getting used to being at home, as described by Bella (36), makes the times when participants need to make plans themselves more difficult. Ezekiel (47) specifically reported feelings of loneliness in the evenings and weekends due to living alone.

These examples illustrate the need for practitioners to see past people's seemingly busy lives, people who are making efforts to fill their time by seeing people and attending groups, but they are not doing what they *enjoy*. They are filling up their time in an attempt to distract from the feelings of loneliness, but it is apparent from these participants that it is not an effective strategy (Ryckebosch-Dayez *et al.*, 2016). Oliver (62) illustrates this, suggesting '*there's always something for me to do*'. Yet for many disabled participants in this study dealing with illness or loss combined with access to limited services can become their main focus, which impacts on their ability to put more energy into enjoying life.

Discussion and conclusion

This study illustrates the complexity presenting itself when attempting to understand pathways into emotional loneliness; when analysing the biographical narratives of disabled participants. Indeed, there is no single, key risk factor which led to any participant becoming emotional lonely. Instead, within the biographical narratives, multiple and intersectional life events can be observed which led to diverse

experiences of emotional loneliness. As has been discussed, an important life event in disabled participants' biographies is what some described as 'loss of ability'. For participants in this study, becoming a disabled person had a significant impact on their lives. Many became unemployed during this period, and for others becoming a disabled person occurred after they had retired from full-time employment. However, becoming a disabled person not only affected their employability but also their relationships with others. The data in this study illustrates that a significant factor in pathways into emotional loneliness was the loss of strong relationships or friendships, as participants were not only alienated from the workplace but also from their chosen leisure activities. From this perspective disability became a key factor in breaking down concrete relationships for participants in this study. From a biomedical perspective the breaking down of relationships is an inevitable effect of becoming impaired (Paul et al., 2006; Rokach et al., 2006). Yet if we apply a social model perspective (Oliver, 2009; Barnes, 2012; Macdonald et al., 2018b), what we see are disabling barriers of exclusion for participants who have become disabled. Within this study, participants could be observed as becoming isolated from the workforce through disabling barriers of exclusion, leading to a breakdown in friendship ties through inaccessible leisure activities, followed by a lack of community services to support individuals becoming active members within their communities (Oliver 2009; Barnes 2012).

Nevertheless, as discussed, disability was not the only key factor that led to the breakdown in social relationships for many participants. There was a clear intersectional relationship between experiences of disability and bereavement. Eight participants in this study indicated that bereavement played a significant factor in their experiences of emotional loneliness and isolation. Within their stories, bereavement often led to the breakdown of strong family ties or relationships. Some participants suggested they did not experience social isolation but only periods of loneliness. Therefore there needs to be recognition that many of our disabled participants were not necessarily socially isolated, but struggled to create meaningful relationships in their daily lives. These findings are consistent with Forrester-Jones *et al.* (2002) who illustrated that the key issue for disabled participants was not a lack of contact but the *strength* of friendships developed.

Finally, the experiences of becoming disabled and the breakdown in friendship or family ties resulted in significant periods where participants reported spending time alone. As Maureen (52) discussed, sometimes she looks out of the window and it's a lovely day and she goes for a walk by herself. Within her narrative she illustrated the need for friendships and someone to share the experience of walking. From this perspective, spending time alone seems to be the first step in feeling emotionally lonely. The data also illustrated that the longer participants spent on their own, the more at risk they were of becoming emotionally lonely. Many participants reported that loss of friendships and the weakening of social connectivity had a significant impact on their self-worth and self-confidence. For

participants with mental health issues this seemed to exacerbate their mental health needs. This loss of self-confidence and the breakdown in external friendships led to some participants withdrawing into the safety of their own home. For them, the outside world became more alien and frightening, which led to a spiralling effect of social isolation and emotional loneliness.

Yet very few participants discussed how social care and health services had successfully intervened in their lives. Although a number of participants had tried to combat experiences of loneliness through joining voluntary groups, this did not result in them building strong friendships or combating their experiences of emotional loneliness. By recognising key risk factors experienced by disabled people in this study, services can develop a system of intervention to support disabled people within their communities. From this perspective we suggest that support is needed to be able to engage with the individual emotional needs of service users, and consider how to involve those who may be lacking in confidence about how to engage socially again. It is therefore important that a multi-agency response is implemented in order to address the social aspects of social isolation (the first step towards emotional loneliness). For example, Tanskanen and Antilla (2016) refer to the psychosocial mechanisms where social isolation can occur, such as in areas of social deprivation. This is where a multi-agency response should be beneficial in order to take a holistic view, but in order to achieve this practitioners and policy-makers need to understand the potential risk factors for social isolation, particularly for disabled adults.

Therefore, the authors suggest that rather than conceptualising emotional loneliness and isolation as inevitable results of having an impairment, it is more beneficial to scrutinise the structural barriers that lead to disabled people being a noteworthy part of this population. By exploring these disabling factors, this may help to emancipate many disabled people confined to their homes due to inadequate support services or discriminatory welfare policies (Oliver 2009; Barnes 2012). To combat social isolation and loneliness for disabled people, we need adequate support in existing and new services, specifically focusing on removing disabling barriers in welfare and community services to foster relationship building and social connectivity. These services should be aimed at supporting disabled people through the transition into living with an impairment as well as living in a disabling environment. These services must not only support the physical needs of individuals living within the community, for example, homecare, but they must also play a fundamental role in supporting wellbeing through fostering inclusive environments and healthy relationships for disabled people who have become, or at risk of becoming, substantially isolated within the current community care system.

References

- Barnes, C. (2012) Social model, past, present and future. In N. Waston, A. Roulstone and C. Thomas (Eds.) *Routledge Handbook of Disability Studies*. London: Routledge
- Bennett, K.M. and Victor, C. (2012) 'He wasn't in that chair': What loneliness means to widowed older people. *International Journal of Ageing and Later Life*, 7, 1, 33–52
- Birks, M. and Mills, J. (2015) *Grounded Theory*. London: Sage
- Care Act (2014) London: HMSO
- Chappell, A.L. (1994) A question of friendship: Community care and the relationships of people with learning difficulties. *Disability and Society*, 9, 4, 319–34
- Charmaz, K. (2006) *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*. London: Sage
- Clayton, J., Donovan, C. and Merchant, J. (2015) Emotions of austerity: Care and commitment in public service delivery in the North East of England. *Emotion, Space & Society*, 14, 1, 24–32
- Cross, M. (2013) Demonised, impoverished and now forced into isolation: The fate of disabled people under austerity. *Disability & Society*, 28, 5, 719–23
- De Vaus, D.A. (2014) *Surveys and Social Research*, 6th Edn. London: Routledge
- Flynn, C. and McDermott, F. (2016) *Doing Research in Social Work and Social Care*. London: Sage
- Forrester-Jones, R. Carpenter, J. Cambridge, P. Tate, A. Hallam, A. Knapp, M. and Beecham, J. (2002) The quality of life of people 12 years after resettlement from long stay hospitals: Users' views on their living environment, daily activities and future aspirations. *Disability & Society*, 17, 7, 741–58
- Halpern D. (2005) *Social Capital*. Cambridge: Polity Press
- Hesse-Biber, S.N. and Johnson, R.B. (2015) *The Oxford Handbook of Multimethod and Mixed Methods Research Inquiry*. Oxford: OUP
- Holt-Lunstad, J. and Smith, T.B. (2016) Loneliness and social isolation as risk factors for CVD: Implications for evidence-based patient care and scientific inquiry. *Heart*, 112, 13, 987–9
- Holt-Lunstad, J., Smith, T.B., Baker, M, Harris, T. and Stephenson, D. (2015) Loneliness and social isolation as risk factors for mortality: A meta-analytic review. *Perspectives on Psychological Science*, 10, 2, 227–37
- Jacobson, N.C., Lord, K.A. and Newman, M.G. (2017) Research paper: Perceived emotional social support in bereaved spouses mediates the relationship between anxiety and depression. *Journal of Affective Disorders*, 2, 11, 83–91
- Kawachi, I. (1999) Social capital and community effects on population health and individual health. *Advanced Sciences*, 896:120–30
- Kearns, A., Whitley, E., Tannahill, C. and Ellaway, A. (2014) Loneliness, social relations and health and well-being in deprived communities. *Psychology, Health & Medicine*, 20, 3, 332–44
- Longman, J., Passey, M., Singer, J. and Morgan, G. (2013) The role of social isolation in

- frequent and/or avoidable hospitalisation: Rural community-based service providers' perspectives. *Journal of the Australian Healthcare & Hospitals Association*, 37, 2, 223–31
- Macdonald, S.J. and Deacon, L. (2019) Disability theory and social work practice. In M. Payne and M.R. Hall (Eds.) *The Routledge Handbook of Social Work Theory*. London: Routledge
- Macdonald, S.J., Charnock, A. and Scutt, J. (2018) 'Marketing madness': Conceptualising service user/survivors biographies in a period of deinstitutionalisation. *Disability & Society*, 33, 6, 849–865
- Macdonald, S.J., Deacon, L. and Nixon, J. (2018) "The invisible Enemy": Disability, loneliness and isolation. *Disability & Society*, 33, 7, DOI: 10.1080/09687599.2018.1476224
- Oliver, C. (2012) Critical realist grounded theory: A new approach for social work research. *British Journal of Social Work*, 42, 2, 371–387
- Oliver, M. (1996) *Understanding Disability from Theory to Practice*. Basingstoke: Palgrave
- Oliver, M. (2009) *Understanding Disability from Theory to Practice*, 2nd Edn. Basingstoke: Palgrave
- Patton, M.Q. (2002) *Qualitative Research and Evaluation Methods*. Thousand Oaks, CA: Sage
- Paul, C., Avis, S. and Ebrahim, S. (2006) Psychological distress, loneliness and disability in old age. *Psychological Health and Medicine*, 11, 2, 221–32
- Prime Minister's Office (2018) Prime Minister commits to Government-wide drive to tackle loneliness. Press Release, 17 January. London: PMO
- Public Health (2015) *Local Action on Health Inequalities: Reducing Social Isolation Across the Lifecourse*. London: Public Health England
- Rokach, A., Lechcier-Kimel, R. and Safarov, A. (2006) Loneliness of people with physical disabilities. *Social Behaviour and Personality: An International Journal*, 34, 681–700
- Ryckebosch-Dayez, A.-S., Zech, E., Cord, J.M. and Taverne, C. (2016) Daily life and coping strategies during widowhood: A diary study after one year of bereavement. *Death Studies*, 40, 8, 461–78
- Shakespeare, T. (2015) *Disability Research Today*. Routledge: London
- Sheldon, J.H. (1948) *The Social Medicine of Old Age*. Oxford: OUP
- Shvedko, A., Whittaker, A.C., Thompson, J.L. and Greig, C.A. (2018) Physical activity interventions for treatment of social isolation, loneliness or low social support in older adults: A systematic review and meta-analysis of randomised controlled trials. *Psychology of Sport & Exercise*, 34, 128–37
- Smith, J.A., Flowers, P. and Larkin, M. (2009) *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage
- Septoe, A., Shankar, A., Demakakos, P. and Wardle, J. (2013) Social isolation, loneliness and all-cause mortality in older men and women. *Proceedings of the National Academy of Sciences*, 110, 15, 5797–801
- Strauss, A. and Corbin, J.M. (1990) *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. Thousand Oaks, CA: Sage
- Tanskanen, J. and Antilla, T. (2016) A prospective study of social isolation, loneliness and mortality in Finland. *AJPH Research*, 106, 11, 2042–8

- Taylor, G. (1999) Empowerment, identity and participatory research: Using social action research to challenge isolation for deaf and hard of hearing people from minority ethnic communities. *Disability & Society*, 14, 3, 369–84
- Townsend, P. (1959) Social surveys of old age in Great Britain 1945–59. *Bulletin of the World Health Organisation*, 21, 583–91
- Valtorta, N.K., Kanaan, M., Gilbody, S., Ronzi, S. and Hanratty, B. (2016) Loneliness and social isolation as risk factors for coronary heart disease and stroke: Systematic review and meta-analysis of longitudinal observational studies. *Heart*, 0, 1–8
- Victor, C.R. and Bowling, A. (2012) A longitudinal analysis of loneliness among older people in Great Britain. *The Journal of Psychology*, 146, 3, 313–31
- Walker, P. and Shaffer, M. (2007) Reducing depression among adolescents dealing with grief and loss: A program evaluation report. *Health & Social Work*, 32, 1, 67–8
- Wengraf, T. (2001) *Qualitative Research Interviewing*. London: Sage
- Wilkinson, R.G. (1996) *Unhealthy Societies: The Afflictions of Inequality*. London: Routledge