'*The thing about vulnerability is it sort of takes on, sort of different levels*': the experience of vulnerability among older people ageing with deafblindness

Introduction

Vulnerability is a well-established analytical concept in environmental science, yet is largely 'under-examined' in social work (Philips, 2021). Nevertheless, because it is related to risk and the need for protection, it is essential for social workers to understand vulnerability, particularly when promoting and protecting people's rights. Notwithstanding the subjectivity evident in determining who is considered vulnerable (Brown 2011), vulnerability itself is a key concept in a wide range of English legislation, policy and practice guidance that seeks to identify and respond to the phenomenon (Fawcett 2009, Keywood 2017). For example, in the criminal justice system, special provisions are made for 'vulnerable witnesses' (see, for example, the Youth Justice and Criminal Evidence Act 1999) and 'vulnerable victims' (see, for example, the Domestic Violence, Crime and Victims Act 2004). In the context of homelessness, identifying an individual as vulnerable may determine a priority need for housing (see, for example, the Homelessness (Priority Need for Accommodation) (England) Order 2002). The concept has also underpinned much adult safeguarding policy and practice in England (Lonbay, 2018), and being identified as vulnerable has sanctioned state intervention (Brown et al., 2017). Notwithstanding the change of terminology in English adult social care legislation from 'vulnerable adult' to 'adult at risk' (s42 Care Act 2014), the way in which vulnerability is understood influences both relationships between social workers and service users, and approaches taken to intervention (Brown, 2017; Fawcett, 2009).

Interest in vulnerability has seen a renaissance in the last decade across different disciplines (Keywood, 2017). Nevertheless, scholarly activity principally concentrates

on policy analysis and theoretical debate (Brown et al., 2017), the latter of which has seen the emergence of the universal vulnerability approach (Brown 2011, Pritchard-Jones 2016), most notably Fineman's development of the 'vulnerability thesis' (Fineman 2008). Fineman (2008, p1) argues that vulnerability is 'universal and constant, inherent in the human condition'. This conception of vulnerability contrasts with definitions focused on the identification of 'vulnerable groups', ordinarily those in need of additional care and support (Mackenzie et al. 2014). To recognise vulnerability as an ontological condition of all humanity, whilst simultaneously acknowledging specific forms of the phenomenon, Mackenzie et al. (2014) developed a taxonomy of vulnerability in which three different, yet non-discrete sources of vulnerability are identified: inherent, situational, and pathogenic. Inherent sources of vulnerability include characteristics such as age, impairment, and sex, whilst situational sources are individual or group social, political, economic and/or environmental situations, which cause or exacerbate vulnerability. A subset of situational sources is pathogenic sources: vulnerability owing to failures in relationships, policy and social support, or situations of oppression (Mackenzie et al., 2014). Despite the development of this theoretical work, Brown (2011, p319) contends that there is a need 'to sharpen up the research agenda on vulnerability'. As little attention has been paid to the lived experience of vulnerability from the perspectives of particular groups, there are calls for further research on the empirical realities of vulnerability from such perspectives. Some such studies exist, for example Abley and colleagues' (2011) exploration of older people's views of the subject, and the study by Heaslip et al. (2016) examining the lived experience of vulnerability among Gypsy, Roma and Travelling communities.

One group considered 'some of the most vulnerable members of our community' (Hutton, 2000, p3) is deafblind people. The complexity of deafblindness becomes apparent when attempts are made to define the condition (Dammeyer 2010). Though it has clinical, legal, and functional definitions (Authors, 2020), literature exploring the impairment offers neither an 'exact nominal definition' (Rönnberg et al. 2002, p137) nor a definition upon which there is clear consensus (Dammeyer 2015). In the study reported here, the definition conceived by the Deafblind Services Liaison Group and subsequently found in English statutory guidance on social care for deafblind children and adults is adopted. This states that persons are considered deafblind:

> if their combined sight and hearing impairment cause difficulties with communication, access to information and mobility. This includes people with a progressive sight and hearing loss (Department of Health 2014, p5).

Globally, the World Federation of the Deafblind (2018) reports that 0.2% of the population lives with severe deafblindness, whilst 2.1% of the population experience milder forms. Drawing on national data sources, Robertson and Emerson (2010) determined there were 356,000 deafblind people in the UK, with more recent estimations suggesting almost 400,000 (Deafblind UK, 2021). Prevalence increases with advancing age (Author, 2019) and the deafblind population is therefore predicted to expand (Deafblind UK, 2021).

Owing to predicted expansion of the deafblind population and the psycho-social difficulties associated with the impairment, Authors (2021) contend that supporting deafblind people is core social work. Furthermore, in England, the Care Act 2014 places explicit obligations towards deafblind people on local authorities. This includes completing specialist assessments, enabling access to one-to-one support where

required, and providing accessible information. In meeting these obligations, practitioners may consider the vulnerability of deafblind people as axiomatic. Nevertheless, a 2017 systematically conducted review located no published research specifically exploring experience of this vulnerability from the perspective of deafblind adults themselves (Author, 2017). This paper presents findings from the first UK based study of the lived experience of vulnerability from the perspectives of older people ageing with deafblindness.

Methods

A qualitative research design was adopted, as this is suited to studies exploring lived experiences from the perspective of the participants and studies of areas about which little is known (Padgett, 2008). Moreover, there are calls for more qualitative research exploring experiences of the deafblind population (Jaiswal et al., 2018). Interpretative Phenomenological Analysis (IPA) was chosen as the most appropriate methodology. Underpinned by phenomenology and hermeneutics, IPA is fundamentally concerned with lived experiences (Shinebourne, 2011). Its third theoretical foundation, idiography, is evident in its detailed and nuanced approach to analysis, which highlights variation between participants (Smith et al., 2009). This was particularly important in this study because of the paucity of research on the topic, and because previous studies with deafblind people are critiqued for homogenising the population (Dammeyer, 2015). Furthermore, IPA's detailed attention to the experiences of marginalised groups can challenge 'prevailing assumptions that others may make about them' (Griffin & May, 2012, p448). IPA was therefore deemed especially suitable, considering statements made about the vulnerability of deafblind people, but limited empirical evidence to support them (Author, 2017). Finally, although its use in social work research is less

developed than in other applied disciplines (Houston & Mullan-Jensen, 2012), Loo (2012) contends that it is especially suited to social work research, owing to a shared concern, amongst the social work profession and social work researchers, to give voice to participant perspectives.

The study was approved by the Health Research Authority Social Care Research Ethics Committee (Reference: *anonymised*). Participants' identifying information is redacted. All interviews were conducted with participants' informed consent, confirmed by their signing the consent form or by consenting in speech or British Sign Language (BSL), which was video recorded. To preserve confidentiality, interview recordings and documents containing participants' details were securely held, and participants' names are pseudonymised throughout this paper.

Participants

Participants were purposively sampled. While IPA studies ordinarily focus on a homogeneous sample, Smith et al. (2009) acknowledge practical and interpretative challenges in determining boundaries of this homogeneity; such challenges are evident in this study. Dammeyer (2015) reports on the significant heterogeneity of the deafblind population and its impact on research in the field. In selecting particular sub-groups of the deafblind population, studies have focused on impairment aetiology (Deuce et al., 2012), nature of onset (LeJeune, 2010), communication method (Chomsky, 1986; Kyle & Barnett, 2012) or the presence of comorbidities (Bodsworth et al., 2011), among other features. This study focuses on people ageing with the impairment, irrespective of aetiology. This choice responds to knowledge gaps and calls for research

on the experiences of this sub-group (Author, 2020). Inclusion and exclusion criteria are listed in Table One.

<<Insert Table One here>>

Recruitment strategies included: raising awareness of the study through use of flyers produced in a range of formats; liaison with specialist national and local organisations; and a request to advertise the study made to professionals and deafblind individuals well known and respected in deafblind organisations, and with whom the first author had an existing professional relationship.

Nine people expressed interest in participating and were sent further details about the research. A total of eight participants fulfilled the inclusion criteria and were recruited to the study. Four were women and four men, aged between 49 and 83. All participants were white British. The age, details about the aetiology and onset of deafblindness, employment status, and language and communication methods of participants are listed in Table Two.

<<Insert Table Two Here>>

Data collection

Data were collected via 18 in-depth semi-structured interviews. Participants were interviewed two or three times. Average interview length was 64 minutes.   The approach to interviewing was informed by the first author's experience as a specialist social worker, learning from a pilot interview, and the limited literature on the

practicalities of interviewing deafblind people (Arndt, 2010; Ellis & Hodges, 2013; Evans, 2017a; Oleson & Jansbøl, 2005). Known strategies for collecting rich data were adopted yet adapted to ensure their usefulness when interviewing deafblind people. This included meeting receptive and expressive communication needs, and adapting enabling techniques, such as use of silence and ways of indicating attentiveness (Author, 2020). Two participants used BSL expressively, and tactile BSL receptively. BSL interpreters were therefore involved in facilitating these interviews. ~~Interpreters' involvement in qualitative research, particularly interpreters of signed language, raises practical, epistemological and methodological challenges (Young & Temple, 2014). The nature of these challenges and how they were managed are explored elsewhere (Author, 2020).~~ All interviews were video recorded and following each interview, notes and reflections were written immediately, capturing contextual information and initial impressions of the encounter.

Data analysis

All 18 interviews were transcribed by the first author. As recommended by Smith et al. (2009), features such as significant pauses, hesitations, 'false starts' and laughter were included, and notes made of initial thoughts on the interaction during transcription. The notion of a verbatim written transcript was problematised when transcribing interviews with participants using BSL. As BSL has no written form (Young & Temple, 2014), producing a written transcript that accurately represents participants' expression and meaning is challenging (Arndt, 2010; Ladd, 2003) and no straight-forward 'how-to' guide offering a clear solution exists (Young & Temple, 2014). The approach adopted involved preparing an 'interim' transcript by repeatedly watching the film of the interviews, similar to that described by Arndt (2010). These interim

transcripts were not solely a record of the interpreter's spoken English, but drew on careful observation of the participants' signs and the first author's knowledge of BSL. Interim transcripts included queries and tentative corrections of the interpreters' translation, recorded in red type. The first author then met with the interpreters, and reviewed the videos and interim transcripts. This offered the interpreters an opportunity to pay careful attention to conceptual equivalence and nuance of meaning (Berman & Tyyskä, 2011; Temple et al., 2006), in addition to responding to queries and correcting errors. The interim transcripts were subsequently amended. Interpreters' involvement in this process enhances trustworthiness of the study (Evans, 2017a; Squires, 2009).

Analysis then followed the iterative six-step IPA process described by Smith et al. (2009). Step one involved reading and re-reading the written transcripts, and where interviews had been conducted in BSL, watching and re-watching the video recordings with the interpreters, providing an opportunity to clarify the data (Schwartz, 2008). This was followed by preparing an exploratory commentary on a hard copy of each transcript, using three analytic tools: descriptive, linguistic and conceptual commenting. Although some researchers use computer software (Vicary et al., 2017), working with hard copies facilitated close engagement with the data, and made it easier to watch interview videos whilst simultaneously viewing a printed transcript. Step three involved the development of emerging themes, by identifying patterns and relationships within the transcript and exploratory notes. The fourth stage of analysis involved mapping how themes identified fitted together. To maintain IPA's idiographic commitment, steps one to four were completed for each participant individually before moving on to the next participant's dataset (step five) and then looking for patterns

across cases (step six). In this final step, connections and relationships between themes and super-ordinate themes across all participants were identified. Throughout the analytic process, a record of thoughts, interpretations and decision-making was maintained.

Findings

Three superordinate themes were identified: felt vulnerability as multi-layered: about, to and when; vulnerability as dependent on the response of others: misunderstanding; and vulnerability as dependent on the response of others: perceptions of incapability. Findings are presented as a narrative account, illustrated by extracts from interview transcripts. Use of the symbol (I) immediately after direct quotations indicates that the words represent an English translation of BSL.

Felt vulnerability as multi-layered: about, to and when

Although experiences of vulnerability differ, participants make sense of these as layered. Participants tell not only what they feel vulnerable about and vulnerable to, but also about situations and times *when* they felt vulnerable. As Faye describes:

> '... the other thing about vulnerability is it sort of takes on, sort of different levels, as well, it's kind of quite a general thing... or it might be sort of like quite specific things... So I think it's sort, like I say, it takes on, sort of several levels'.

Feeling vulnerable about

Although not felt constantly, some participants describe general feelings of vulnerability, associated with worries or concerns about broad matters such as one's job or health. Participants also feel vulnerable about the future. For some, this is associated with not knowing whether further sensory loss will occur. However, it is not

just further deterioration in sight or hearing that contributes to such worries, but also the challenges such deterioration may bring:

> 'It is quite a daunting thought... if my sight got worse and my hearing got worse, how would I manage?' (Rose).

For some participants, general feelings of vulnerability develop as the cumulative outcome of previous experiences. Phillip describes how ongoing mobility difficulties make him 'feel extremely vulnerable' but also 'all contribute to [his] general feeling' of vulnerability.

Feeling vulnerable to

All participants identify specific outcomes to which they feel vulnerable, illustrating a characteristic of the phenomenon as potentiality rather than actuality. While Phillip describes feeling vulnerable to 'all sorts of things', all outcomes that participants highlight feeling vulnerable to are negative. One set of outcomes described is physical harm, including cuts and burns and dangers related to preparing and eating food:

> 'If you eat something and you haven't been cooking it properly, and it's got ice in it, it can make you very ill' (Mike).

Further sensory loss is also an outcome to which participants feel vulnerable, particularly as changes in vision and hearing are experienced throughout their lives. This is not unique to those with acquired progressive conditions, such as Usher syndrome, but also those with congenital deafblindness: Rose tells of the 'fear of losing [her] hearing completely'.

Isolation or increased isolation is identified by some participants as an outcome to which they feel vulnerable. This is associated with being 'othered', the phenomenon of

perceiving an individual as inherently different to oneself or others in society (Canales, 2020), as well as with social interaction difficulties related to communication and deafblindness:

> 'I worry that people will perceive me as being somebody in a world of their own' (Faye).

While Caroline discusses negative outcomes, unlike other participants, for her these are outcomes she feels 'at risk of' rather than factors engendering felt vulnerability. Caroline only feels vulnerable at specific times when other elements are present.

Feeling vulnerable when

All participants offer accounts of times *when* they feel or have felt vulnerable. These stories dominate their interpretations of their experiences. Although telling of times of worry, fear and panic, participants also describe times of relief, security and safety, emphasising the transitory nature of their felt vulnerability. These times can be fleeting moments, a period of time or even a time yet to come:

> 'I knew I was getting in the way, and I just felt quite vulnerable at that particular moment' (Faye).

> 'I didn't feel safe for the last two years. I told my daughter… She came to live with me… I feel comfortable, feel safer, feel better' (I) (Celia).

> 'Not yet, but it could come… I don't at the moment feel vulnerable' (Caroline).

Participants' accounts reveal the situational and setting specific nature of felt vulnerability. The experience is not centred on deafblindness, but rather consequent on the situations and settings in which participants find themselves. While unique to each participant, data indicate shared elements of the vulnerability felt: social settings; losing control or being controlled; inability to withstand; lacking the full picture; and unavailable or ineffective support.

Social settings

Conversation can be rendered hard work because of the impact of deafblindness on receptive communication, and because anxieties arise in relation to mishearing, responding inappropriately and consequently appearing foolish. Furthermore, Rose explains how problems initiating conversations result in her exclusion from social interaction:

> 'I find it very difficult to, erm, join a, join a group that are already talking... the reason being that I can't interact because I don't get eye contact... you're excluded until you can make contact'.

Sight loss poses unique communication challenges for BSL users (LeJeune, 2010). Celia and Anthony describe a sense of isolation within Deaf community social settings, associated with such challenges. Anthony explains how Deaf people's inability or unwillingness to use tactile BSL, and consequent reduced quality of interaction, contribute to his vulnerability:

> '... a Deaf person... might tap me on the shoulder and say hello... spell my name... but then they go off to someone else, and I'm left on my own... Deaf people want to be able to just sign and communicate, and using tactile sign language can be difficult... I understand why, but the isolation comes from that breakdown' (I).

Heterogeneity of the deafblind population and associated plethora of languages and communication methods used by deafblind people contribute to situations in which social interaction with other deafblind people is not necessarily easier but more problematic. Interaction with other deafblind people is also no guarantee of social relationships or friendship:

> '... there isn't anybody that I can interact with, other than with other deafblind groups... But... the fact that somebody's sharing a hearing and sight impairment doesn't mean you're going to become bosom buddies' (Caroline).

Losing control or being controlled

Participants describe feeling vulnerable when sensing they are not in control or are being controlled by others. Anthony's interpretation of vulnerability as being 'about control [or] somebody controlling' is illustrated by his lack of felt vulnerability when travelling alone using taxis, because he maintains control by knowing what to do:

> 'Vulnerability means somebody doesn't know what to do, whereas I know what to do… if you tell me that I need to go out on my own, I'll say, 'OK, please phone a taxi, take me there, and how much? I make arrangements… I'm not vulnerable… Vulnerability implies that you're lost and don't know what to do' (I).

Some participants maintain control by establishing routine. Disruption of routine precipitates a sense of lost control and concomitant feeling of vulnerability.

Inability to withstand

It is not necessarily the challenges participants face, but rather whether they feel able to withstand them, that generates felt vulnerability. Tangible factors such as supportive family and intangible factors, such as one's own cognitive ability or prayer, enable participants to feel safe, even in settings and situations otherwise described as engendering vulnerability. Although he describes isolation as the 'highest level of vulnerability', it is inability to cope with isolation, rather than isolation itself, that leads Anthony to experience vulnerability:

> 'I can cope with my isolation… whereas vulnerability, hmm [pause]. If vulnerability came before isolation, then you would be, it implies weakness and helplessness… With isolation I help myself, I pull myself up' (I).

Ageing is also important in relation to participants' feelings about their ability to withstand certain things. Rose describes feeling better able to withstand 'the knocks you get' when she was younger. Factors beyond their own ability also impact on participants' capacity to withstand life's challenges, including having limited resources,

such as a reduced network of family or friends and little or no formal support. For

Caroline, retirement diminishes her ability to withstand challenges:

> 'When you give up work… there's nothing, unless you've got a ready built circle of friends, and I've not been able to do that… either because I was working, or because I was dealing with children… so I didn't see the need to make friends, and it was too hard to make them, because they couldn't cope with my hearing plus my sight impairment… So it's harder now being retired'.

Lacking the full picture

Participants experience vulnerability when they lack what Anthony describes as 'the full

picture'. This is partly the result of narrowed communication and limited access to

information, phenomena associated with deafblindness, and partly consequent on

others' failure to provide information explicitly, including that which hearing-sighted

people may acquire in childhood. In the context of health worries, Anthony describes

how pain or discomfort may provide half the picture but being unable to see the colour

of his urine, for example, means he lacks the full picture, which would help him

determine the nature of any concerns.

Contrastingly, participants describe how having access to the full picture diminishes felt

vulnerability and fosters feelings of safety and security. Having the full picture appears

to enable participants feel in control or to promote their ability to withstand, and

therefore these elements of experience seem interrelated. Anthony explains how felt

vulnerability when travelling alone arises because he does not 'get full information'. He

adds that when his guide communicates necessary information to him prior to any

journey, such as timetables, he can travel on trains alone and it helps to 'keep me safe'.

Participants describe feeling vulnerable when they lack the full picture in relation to their immediate environment. For those with residual hearing, it is not unexpected sounds themselves that generate anxiety, but rather being unable to identify their cause or location owing to sight loss. Being unaware of others' presence similarly provokes fear:

> 'I'm frightened in case someone approaches me from behind, I can't hear them. I don't know that they're there, I have to look around... I jump' (I) (Celia).

The experience of vulnerability when in unknown places was shared by all participants. This includes being lost or in a completely unknown environment, being with unknown people, and visiting known environments that have since changed.

Unavailable or ineffective support

Participants describe needing help with various activities, with some interpreting need for such support as dependence. Although some identify increased dependence as something they feel vulnerable to, it is not being dependent itself that generates felt vulnerability, but rather being in situations when support upon which one is dependent is unavailable. For Rose, unavailability of assistance is the 'daunting part'. Felt vulnerability is especially acute when ordinarily available and effective support is withdrawn. Faye recalls an experience when her husband left her alone temporarily in a theatre, in order to retrieve his dropped car keys:

> 'But just in that moment he abandoned me, and I suppose it was quite a shock really that he'd just done that. Erm, so it was sort of like the crutch had been taken away at that moment... I'm used to having him there to, to help me'.

It is not just the absence of human support upon which one depends that can engender feelings of vulnerability. For example, participants comment on the impact of fading or absent white paint used to mark out steps. Withdrawal of mainstream facilities can also

have an adverse impact:

> '… an announcement comes on the bus saying, 'The next bus stop is closed' now, instead of having temporary bus stop there, near the bus stop… I still have to get off with a white stick, so I know where I am. You go to the next bus stop. That's no good to me, and lots of other people, we don't know where we are… That's one way of being, of feeling vulnerable' (Philip).

When support is available, participants' feelings of vulnerability do not emerge, are diminished, or are replaced with felt safety and security. Despite Celia feeling vulnerable when alone, knowledge that support will *become* available seems sufficient to diminish these feelings:

> 'When my daughter goes to work… I know I'm alone, but I know she will come and be there… When she [daughter] wants to go out, she always says, 'I'm going to be back in two or three hours, or she gives me the time. So I know to look at the clock, and I know I'm going to be OK… because my daughter will be here soon. That's good… I can control myself' (I) (Celia).

While for most participants available support diminishes or removes felt vulnerability, Caroline describes diametrically opposed experience: engagement with support is when she 'actually start[s] to become more vulnerable'. She describes fears of overprotection, related to social care practitioners thinking 'they know what's best'. Engagement with specialist services and organisations heightens awareness of her dual sensory loss, which has an 'insidious' effect on her self-perception: she begins to question her own abilities and sees herself as someone 'who needs to be looked after and protected'*:*

> 'I'm walking with erm a friend who is [specialist organisation] trained now, err, who used to be a communicator-guide. So I hold her arm… she'll say, 'Watch that bush there', or 'Mind this car's, erm, wing mirror sticking out', and you think, you have to bite your tongue, because you really want to say, 'I don't need you to do that, just, you know, stop thinking about my needs all the time, and that's actually making me feel vulnerable''*.*

Vulnerability layers as interrelated

In making sense of their experiences of vulnerability as layered, participants do not

understand these layers – vulnerable about, to and when - as discrete. They are overlapping and interrelated. For example, participants describe feeling vulnerable when isolated and feeling vulnerable to isolation. Similarly, just as participants explain feeling vulnerable in situations when they experience a sense of losing control or being controlled, such loss of control is a negative outcome that participants describe feeling vulnerable to. This relationship between the 'vulnerable when' and 'vulnerable to' layers of experience is also apparent in participants' discussions about unavailable support.

Participants' responses to different layers of vulnerability can also interact, such that one felt vulnerability is diminished while another is exacerbated. Attempts to reduce felt vulnerability, by avoiding situations when such feelings occur, serve to increase the potentiality of the negative outcomes to which participants feel vulnerable. Rose illustrates this interaction as she describes conflicting views on using a symbol cane:

> 'On the one hand, erm, it does give me sense of security, but on the other hand, erm, I feel, well do I really need it... And also I am also aware of the fact that it does draw attention to me. On the other hand, that can be an advantage... but not always'.

Caroline also illustrates interplay between vulnerability layers. She describes feeling vulnerable to isolation and loneliness, yet her felt vulnerability when in social situations, associated with the risk of appearing stupid, is prevailing. She therefore eschews such situations by avoiding them completely or by presenting as unsociable:

> 'I would quite like to talk to them, or talk to somebody on a bus. But I can't take the risk... The risk is, I think, of somebody talking back to me and not, either I misunderstand completely or I don't answer, and they'll either think I'm stupid or they'll think I'm very snooty. Which, neither of those is true. So better not to engage in conversation and let them think that you're... snooty. Erm, I think the overriding thing is you don't want to appear stupid'.

Vulnerability as dependent on the response of others: misunderstanding

Feeling, being and expecting to be misunderstood

Although participants recall being misunderstood in childhood, the experience is ongoing in their lives. They describe being misunderstood by relatives, the Deaf community, health and social care professionals, and strangers. Reflecting on the recurring nature of these experiences leaves Rose to ponder:

> 'How many people really understood me... this is part of the difficulty, I felt misunderstood'.

Some participants describe the extent of the impairment being misunderstood; this is particularly focused on sight loss. Celia believes that 'Deaf people really don't understand how bad I am'. Phillip often feels that people 'think I can see more than I can' and interprets difficult situations as centred on the misunderstanding of the extent of his sight loss.

Feeling that the impact or nature of the impairment is misunderstood is also described. Recalling her college days, Rose tells of fellow students not realising what her 'limitations are'. Phillip critiques the local authority's social care survey he was asked to complete, noting how a perceived misunderstanding of the impact of deafblindness renders it difficult for his needs to be accurately captured:

> 'On a recent survey I had to fill in, there's a, do you need help indoors? I'm fine indoors in my own home thank you. But what about some, another home, place, in [local area]. It could be, erm, shops, it could be town hall, anything, I need help, all the time'.

Misunderstanding of linguistic and communication-based needs can lead to the experience of what Anthony calls 'breakdown'. Caroline recalls a moment of 'terror' when her doctor misunderstands her communication needs:

'… the doctor said something, and I said, 'Oh, I'm sorry, I'm deaf'. So he stopped speaking and just mouthed everything… I just looked at him in terror, and I said, 'I can't cope if you don't give me some words, some sound''.

Participants also describe their behaviour being misunderstood. Desiring physical contact and needing tactile receptive communication, Anthony expresses concerns about people misinterpreting such contact as sexual in nature. When once left alone in a theatre, although feeling vulnerable to getting lost and falling, others questioning her behaviour as she flounders is important in Faye's interpretation of the experience:

'I'm trying to put myself in their shoes, trying to imagine them looking back at me seeing this person floundering and not really understanding why I was doing that… I was thinking about what, what, what's this person doing, why is she not moving with the rest, why is she not, you know, like everybody else, and moving along, why is she behaving awkwardly'.

In seeking to lessen misunderstanding, some participants use visual symbols of deafblindness, for example, red and white canes, and some tell others of their impairment directly. Nevertheless, participants explain that such actions are not always effective, as they describe an ongoing sense that their deafblindness is unrecognised or misunderstood:

'But you'd be amazed at how many people still don't seem to know or understand what a white stick is for' (Rose).

Even when told of the impairment, misunderstanding is persistent:

'I was talking to [my sister] about, about this [deafblindness], and she said, 'But you're not deafblind', I said, 'Well according to the Department of Health I am'. I explained what it was about, the communication, mobility. She said, 'But you can communicate', and I said, 'Yes, but look just how much difficulty I had' (Caroline).

Explaining misunderstanding

Participants seek to understand such misunderstanding, ascribing it to ignorance and unconscious incompetence. However, difficulties understanding deafblindness are acknowledged and some participants describe their own misunderstanding:

> 'I didn't understand… I had to learn about my condition… I kind of appreciate that other people are not really going to find it easy to understand' (Faye).

As a minority impairment, deafblindness may be outside the experience of social workers and other welfare practitioners. While an inpatient in a mental health hospital, Phillip describes misunderstanding by clinicians, but recalls the psychiatrist commenting that they have 'never seen anyone like you before come in, somebody with sight and hearing loss'. For Caroline, definitional complexity contributes to her experience of being misunderstood and some participants interpret the heterogeneous nature of deafblindness to have a role in their experiences of misunderstanding. A further factor that participants identify as contributing to misunderstanding is the invisibility of the condition. For Phillip, the 'hidden' nature of deafblindness is experienced as 'double disability'.

Outcomes of misunderstanding

Irrespective of the reasons ascribed to experiences of being misunderstood, participants also describe a range of resultant outcomes, which further contribute to their felt vulnerability. Expecting misunderstanding, participants sometimes feel reluctant to tell others of their deafblindness. The expectation of misunderstanding is also significant in informing participants' decision-making about equipment use:

> 'I don't put red bands on my white cane, because… either people don't know what it means, or if they do know what it means, they won't come and help me, because they think I won't be able to hear or see anything, so there's no point' (Caroline).

Participants share stories of when they have felt that the extent of their deafblindness is disbelieved, because of misunderstanding. Fearing that her condition will be disbelieved, Rose explains how she presents as more impaired than she is:

'… if there's somebody here in the room with me, and something glittering was on the floor, 'cos of the way of the light shining on it, I bent down picked it up… I would feel most vulnerable, because I would immediately think, well they'll think why, why did she see that? She must be able to see better than we think… And it therefore means, makes it quite difficult sometimes to know, would it be, would it better just to ignore that and pretend I didn't see it?'

Participants explain how misunderstandings result in situations where others perceive them as 'rude', 'inconsiderate', or 'unsociable'. Misunderstanding is also understood by participants as contributing to difficulties receiving support. Anthony explains how misunderstanding of his needs, within the mainstream older people's supported accommodation where he lives, results in ineffective support:

'… there's the emergency cord [points to emergency pull cord in flat], I put it on the top shelf, and they told me off, and they said, 'No, it has to hang', and I said, 'No, it's my mobility, I follow the wall [indicates with hands feeling around the wall] and I'll end up pulling it. It will be a false alarm, everybody would come to the flat, and nothing wrong'. So I put it on the shelf' (I)

Vulnerability as dependent on the responses of others: perceptions of incapability

Feeling, being and expecting to be perceived as incapable

Feeling vulnerable when others are perceiving you as incapable is described by all participants. While they recall childhood experiences of such vulnerability, being perceived as incapable continues throughout their lives, irrespective of their education, career or experience. Some participants state explicitly that they feel other people may think of them as stupid. Participants describe people becoming impatient when they fail to respond to visual prompts, such as signs to move forward in post office queues, and report situations in which they felt patronised.

This vulnerability is also evident within a social care context. Mike angrily tells of a time he was 'shouted at' by a care worker and described to others as being unable to 'handle

my money' for simply making a mistake. Anthony explains how support workers expect

him to be incapable, resulting in unrequired offers of assistance:

> 'Like the manager here… She thinks she's helping. No, I can do it by myself. She's amazed, 'You can do it?' Then she goes back to the old people, she works with old people, she helps them. I say, 'No, I can do it'' (I).

Faye's worries concerning lost opportunities to demonstrate capability are central to

her felt vulnerability about losing her job:

> 'I want to erm, still show that I'm capable of working, that I can [pause], you know, I'm capable of earning my own living'.

As participants continue to experience the perception of incapability throughout their

lives, they describe feeling that they are 'dismissed', 'ignored', 'pitied', 'disrespected',

'second-class' or 'less than' others. Perceptions of incapability also have a wider impact.

Anthony refers to an airline company's rule refusing him permission to fly

unaccompanied, which leaves him feeling vulnerable to discrimination. He interprets

the policy to be informed by the assumption that all deafblind people are incapable.

Needing and valuing recognition of capability

Having experienced the feeling of or having been perceived as incapable throughout

their lives participants seek out recognition of their capability. When asked how she

would like to be seen, Caroline's first response is 'competent and capable'. For Faye,

recognition of her abilities by social services' staff is welcome:

> 'Sometimes they're quite encouraging as well… some sort of say, 'well, good for you being employed''

Discussion

Participants have unique experiences of feeling vulnerable, but all make sense of these as layered, describing not only what they feel vulnerable about and to, but also times when they feel or have felt vulnerable. The latter layer dominates participants' interpretations of the phenomenon. Although describing such times, they also describe times of safety and security, revealing their experience of vulnerability as transitory. This echoes other studies' findings, in which older and disabled individuals reject the notion that vulnerability is an immutable state (Abley et al., 2011; Parley, 2010), supporting arguments against categorising particular groups as permanently vulnerable in professional, legal and political spheres. Such categorisation, focused solely on impairment as an indicator of vulnerability, provides an inadequate understanding of experience. There are calls to pay more attention to the particular risks adults are vulnerable to, rather than the mere identification of certain people as vulnerable (Authors, 2020). However, policymakers should consider adopting a layered approach when defining vulnerability: about, to, and when. Assessment of these layers, and how they interact in people's lives, may offer social workers a more nuanced understanding of deafblind people's experience and assist in determining what matters to them.

Times when participants felt vulnerable are situation and setting specific, and both fleeting moments and extended periods are reported. Situations and settings creating vulnerability are individual to each participant. Nonetheless, they describe shared elements of the experience, which illustrate the non-distinct nature of the three sources of vulnerability in Mackenzie and colleagues' (2014) taxonomy: inherent, situational and pathogenic. For example, difficulties initiating and engaging in conversation in social settings produce fears of misunderstanding, being left alone or appearing foolish:

the situational amplifies the inherent source of vulnerability. For those using tactile communication, other people's inability or unwillingness to use such communication methods engenders pathogenic vulnerability at an interpersonal level, albeit that such inability or unwillingness is not necessarily deliberate or malevolent.

Although a lack of available or effective support for deafblind adults is associated with reduced quality of life (Ehn et al., 2019), findings from the present study illustrate how such unavailability is also associated with felt vulnerability. It is not because of dependence upon support that participants feel vulnerable, but that the support is not made available to them. Drawing on the theorising of Scully (2014), the source of vulnerability in such situations is also pathogenic. Scully (2014) maintains that dependence upon others is a reality of human experience, and the fact that disabled people may need assistance with tasks that the majority do not, does not in itself negate their autonomy. Nevertheless, to maintain their autonomy, 'the contribution by another person or service [must] actually be made – it is a vulnerability' (Scully, 2014, p213). She goes on to highlight distinctions between the dependencies of the non-disabled majority, giving the example of good roads facilitating one's commute to work, and those of disabled people, giving the example of braille signage. The dependencies of the majority are met unquestioningly (if they are even seen as dependencies), while those of disabled people are perceived as an indicator of increased vulnerability, and may not be met; this, Scully (2014) argues, is political choice. In perceiving participants' dependence on specialist support as evidence of their increased vulnerability, and deeming it, in Scully's words 'a non-permitted dependency', a further political and economic decision is then made in relation to whether it is met. It is reported that

deafblind people's needs are sometimes unmet, despite legal entitlement (Waheed, 2016): their vulnerability is the result of a socio-political injustice, and thus pathogenic.

Caroline's dichotomous interpretation of use of support as engendering felt vulnerability is similarly pathogenic: a response intended to ameliorate vulnerability generates new ones (Mackenzie et al., 2014). Deafblind people have described feeling vulnerable to overprotection (Hersh, 2013a; LeJeune, 2010), and Caroline similarly explains how her use of support creates vulnerability, as she begins to question her own abilities and becomes increasingly aware of her impairment.

Other people's inconsiderate and hurtful attitudes were so significant to adults with acquired deafblindness participating in Schneider's (2006) study, that they were deemed more problematic than the impairment itself, and the world considered 'hostile'. In the present study, only two participants describe encountering what they perceive as hostility. Nevertheless, all participants explain how felt vulnerability can be dependent on the responses or perceptions of others, and these centre on misunderstanding and the perception of incapability.

Alley and Keeler (2009:3) contend that deafblindness is an 'unrecognised disability'. Lack of recognition contributes to misunderstanding of the condition (Author, 2019), yet this is maintained at an international level. The World Federation of the Deafblind (2018) reports that, from the data available, only 37% of countries (n=50) officially recognise deafblindness as a distinct impairment~~disability~~. Participants in the present study describe being, feeling and expecting to be misunderstood throughout their lives: a phenomenon Gill (2006, p187) terms the 'alien factor', and one she considers

significant in the construction of disabled people's vulnerability. In making sense of such misunderstanding, participants seek to explain its occurrence. They identify various reasons, including the invisible or hidden nature of deafblindness, a factor similarly reported in qualitative inquiries into the experience of adults with other invisible impairments (Lingsom, 2008; Mullins & Preyde, 2013; Stone, 2005). Common to others with invisible impairments, and those deafblind people acquiring visual impairment in later life (Hersh, 2013b), some participants describe an associated need to tell others, but a fear that doing so may be met with disbelief. Within the literature on invisible impairments are descriptions of people attempting to present as non-disabled, a term Goffman (1963), in his work on stigma, terms as 'passing'. While attempts at disguising deafblindness, particularly hearing impairment, are observed among participants in the present study, presentation of oneself as more impaired, to avoid misunderstanding and disbelief, is also reported.

Associated with 'a distrust of mere spoken claims to disability', Lingsom (2008, p9) observes disabled people making use of visual markers, such as white canes, as a way of telling others. Phillip engages in similar behaviour, using both his cane and braille watch. Nevertheless, participants also describe declining to use such aids. Some studies report that fears of stigma and difficulties accepting one's deafblindness are core reasons for such refusal (Ellis & Hodges, 2013; Hersh, 2013b). The present study highlights how fears that the meaning of such aids will be misunderstood, therefore rendering the equipment ineffective or provoking unhelpful responses, are also contributory factors.

All participants describe feeling vulnerable when and to people perceiving them as incapable or incompetent, a finding echoed across the deafblind literature (Author, 2017) and wider disability literature (Gill, 2006). Scully's (2014) notion of 'ascribed global vulnerabilities' assists our understanding of how some participants interpret the origins of such perceptions. This concept refers to the extrapolation of genuine vulnerability in one element of a disabled person's life to its entirety (Scully, 2014). It appears to operate at interpersonal and policy levels. For example, reflecting the former, Mike explains how support workers question his ability to manage money, interpreted as based on his need for support with other tasks. Illustrating the phenomenon at a policy level, Anthony understands an airline company's policy of not allowing disabled people to fly alone, as based on a blanket assumption that they are incapable of managing their own safety. Enhancing the impact of the ascription of global vulnerability in this instance, it appears deafblind people are perceived as a homogenous group. Seeing himself as capable of managing his safety when appropriate communication support is provided, Anthony laments the lack of 'criteria' to differentiate between deafblind individuals. As Smith (1993) argues, the homogenisation of the deafblind population, which includes congenitally deafblind children with additional intellectual impairment, risks increasing the vulnerability of the 'just' deafblind. Whilst there are calls for greater awareness of deafblindness among social workers (see, for example, Evans, 2017b), and findings here support such calls, any awareness training should therefore pay careful attention not to homogenise the deafblind population. Consideration should be given to the involvement of deafblind people in training activities, such that it is centred on relationships and knowing individuals, rather than just knowledge about the impairment.

Irrespective of the nature or cause of perceptions of incapability, it has particular significance in the participants' experiences of vulnerability. Such is the fear of being seen in this way, some participants describe avoiding situations in which it may occur, albeit that such situations are desired. Consequently, as vulnerability to the perception of incapability is diminished, vulnerabilities associated with isolation and loneliness are realised and intensified. Allowing herself to be vulnerable to the perception of incapability by engaging in the social interaction that she so desires, might not only reduce Caroline's isolation, but also provide an opportunity to express her competence and be recognised by others as such. This illustrates the position of Anderson (2014, p135), who argues against the presentation of vulnerability and autonomy as oppositional, and posits that the 'realisation of autonomy is ineluctably bound up with certain forms of vulnerability'. To promote deafblind people's autonomy, social workers should not therefore dismiss experiences of vulnerability, but explore coping strategies and reject assumptions of incapability based on impairment.

Strengths and limitations

Study authenticity is enhanced by meeting participants' communication needs, opportunities to interview participants two or three times, and analytical rigour. Though some argue that phenomenological approaches do not work well in cross-language studies (Padgett, 2008), the first author's knowledge of BSL reduced 'linguistic distance' from the data. Nonetheless, commenting on transcripts was in written English, and 'member checking' by sharing transcripts with participants were not possible.

Although statistical representation is not the study's aim, sample size is small. All participants were living in the community and were in contact with deafblind

organisations. However, they differ in age, aetiology of deafblindness, and order and timing of impairment onset. Such differences may impact on their experience. Nevertheless, IPA's idiographic commitment enabled exploration of the uniqueness of each participant. Limiting description of participants' biographical details may affect transferability of findings, but was necessary to maintain anonymity.

Particular disadvantages faced by deafblind people from Black and Minority Ethnic communities are reported (Joule & Levenson, 2008). Their roles in influencing the vulnerability experience were not explored, as all participants were white British.

Conclusion

The dearth of research on the experience of vulnerability from the perspectives of those who experience it is well documented. This study explored the lived experience of the phenomenon among older people ageing with deafblindness. Findings show how participants interpret their vulnerability as layered, describing what they feel vulnerable about, what they feel vulnerable to and when they feel vulnerable. The latter layer is predominant: participants' experiences of vulnerability are time-limited, and situation and setting specific, and reflect Mackenzie and colleagues' (2014) taxonomy of vulnerability. Findings strengthen arguments against categorising particular groups, including deafblind people, as permanently and immutably vulnerable. Situational and pathogenic sources of vulnerability include the responses of other people, particularly experiences of being misunderstood or perceived as incapable. The layers of vulnerability are not discrete: participants' compelling stories demonstrate how they can be combined and how avoidance of one vulnerability can exacerbate another. Assessment of these layers, and how they interact in people's lives, may offer social

workers a more nuanced understanding of deafblind people's experiences and assist in determining what matters to them. Assessment should also explore coping strategies, and assumptions of incapability based on impairment rejected.

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