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AGEING WITH DEAFBLINDNESS

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Introduction

As a complex impairment with many different causes (Bodsworth, Clare, Simblett, & Deafblind, 2011), the term deafblindness has legal, clinical, and functional definitions. Many terms are used to describe the phenomenon, including dual sensory impairment, deafblindness, and combined hearing and vision loss (Wittich, Southall, Sikora, Watanabe, & Gagne, 2013). It affects people in different ways. Owing to its complexity, it is not surprising that deafblindness is described as an 'unrecognised disability' (Alley & Keeler, 2009, p. 3). The term 'deafblind' can be used to describe the continuum of combined hearing and sight loss, irrespective of the age and order of onset of each impairment and the severity of each loss (Ask Larsen & Damen, 2014; Wittich et al., 2013). As such, people who are deafblind vary con- siderably (Simcock, 2017). Nevertheless, what deafblind people have in common is deprivation in use of the distance senses (sound and sight) (McInnes, 1999), resulting in difficulties with communication, accessing information and mobility. The integrated experience of aging and deafblindness is captured by Pollington (2008, p. 32), 'Getting older is another change that I am living through. I have found old age an ambiguous process. I cannot divorce ageing from deafblindness because that is what I am'.

While establishing the prevalence of deafblindness is challenging because of this definitional com- plexity, most researchers agree that prevalence rises with increasing age (Wittich & Simcock, 2019). In developed countries, older people with acquired deafblindness form the largest sub-group of the deaf- blind population (Munroe, 2001; Robertson & Emerson, 2010; Wittich, Watanabe, & Gagne, 2012). However, this chapter considers those older people who are ageing with the impairment, about whom little is known (Simcock, 2017). After discussing the limited literature about this group, we argue that they challenge the division usually drawn between congenital (people who are born deafblind) and acquired deafblindness, before analysing the commonly reported experiences of ongoing change and adaptation. We then describe the concerns that people who are ageing with deafblindness have about the ability of health and social care services to meet their particular needs, before concluding the chapter by recommending next steps in research, policy, and practice. The chapter ends by suggesting further readings on the topic.

Background Literature

Writing in 2001, Rönnberg and Borg (2001, p. 74) observe that '[f]rom an international perspective, the population of deaf-blind [had] received little research attention'. Just as Moll and Cott (2013) note a focus among rehabilitation services on children with cerebral palsy rather than older adults with the

condition, the provenance of deafblindness campaigning organisations came from shared concern about the needs of deafblind children; it was not until the 1980s that organisations explicitly highlighted the needs of older deafblind people (Wittich & Simcock, 2019). Wittich, Jarry, Groulx, Southall, and Gagne (2016) report that the research community had a similar approach, initially focusing on the needs of deafblind children, resulting in few studies of the older deafblind population. Particularly little is written about older deafblind people living in low and middle-income nations (Jaiswal, Aldersley, Wittich, Mirza, & Finlayson, 2018; World Federation of the Deafblind, 2018), despite the increased likelihood of early onset impairment in such countries (Westwood & Carey, 2018). Furthermore, there are specific calls for more qualitative research exploring deafblind people's experiences (Jaiswal et al., 2018; Schneider et al., 2011; Tiwana, Benbow, & Kingston, 2016) and for further inquiry into the impact of the impairment on family members (Lehane, Wittich, & Dammeyer, 2016). Consequently, writing over a decade after Rönnberg and Borg (2015) argues that research in deafblindness remains in its infancy.

The existing research on deafblind older people has been described as being of variable quality (Heine & Browning, 2015; Saunders & Echt, 2007). A particular critique of current research is the failure of study authors to make explicit the specific sub-group of the deafblind population concerned, which makes the synthesis of material, and ability to draw conclusions from it, problematic (Dammeyer, 2015; Rönnberg & Borg, 2001; Simcock, 2017; Tiwana et al., 2016). The majority of literature on older deafblind people focuses on those people with late-life acquired deafblindness (Wittich & Simcock, 2019); this reflects demographic changes of ageing societies which have encouraged research activity with this group (Wittich & Simcock, 2019). Nonetheless, other groups of older deafblind people, who would be considered to be ageing *with* the impairment, are described in English health and care policy (Department of Health, 1997). This policy attention includes: those people living with sight impair- ment who subsequently acquire hearing loss; deafened or hearing impaired older adults using speech to communicate, who subsequently acquire sight loss; older culturally Deaf people using sign language who subsequently acquire sight loss; and those who have been deafblind for all or the majority of their life. As noted in the introduction, determining the prevalence of deafblindness is complex, and the number of adults ageing with the impairment is not known (Wittich & Simcock, 2019), although con- temporary diagnostic and treatment advances may expand any 'ageing with' population (Westwood & Carey, 2018).

Despite the increase in studies on late-life acquired deafblindness, few researchers have involved older people who are ageing with the condition. In a systematically conducted review, Simcock (2017, p. 1703) found 'no studies [that] focus specifically or solely… on the experience of ageing with deafblindness'. What was identified were studies on the experiences of deafblind people, which include people who have aged with the impairment (see, for example, Damen, Krabbe, Kilsby, & Mylanus, 2005; Dammeyer, 2010; LeJeune, 2010; Oleson & Jansbøl, 2005), literature authored by social work practitioners, drawing on practice experience and interviews with deafblind people (see, for example, Miner, 1995, 1997; Wickham, 2011), and personal/autobiographical accounts, written by those ageing with the impairment and published in various journals and other media (see, for example, Bejsnap, 2004; Pollington, 2008; Stiefel, 1991; Stoffel, 2012). This material details particular differences between the needs and experiences of those with late-life acquired deafblindness and those ageing with the impairment (Simcock, 2017). Akin to those people ageing with various impairments, those ageing with deafblindness are reported to experience: ongoing change and the consequent need for adaptation; a particular reciprocal relationship between the ageing process and the impairment; and a sense that while one can learn adaptive strategies, living with an impairment for a long time does not make this easier. As Simcock (2017) contends, these experiences may be considered features of what Putnam (2012, p. 92) defines as the 'uniqueness of ageing with disability'. Drawing on the existing body of work and more recent doctoral study involving adults ageing with deafblindness undertaken by the first author (Simcock, 2020) and supervised by the second, this chapter now turns to explore its first key point:

that those ageing with deafblindness are a hidden population that challenge the division usually drawn between congenital and acquired manifestations of the impairment.

A Hidden Population Challenging the Congenital: Acquired Divide

Although research exploring ageing with a single sensory impairment has been undertaken (Age UK & Royal National Institute of Blind People, 2015; Jeppsson Grassman, Holme, Taghizadeh Larsson, & Whitaker, 2012; Young, 2014), having more than one sensory impairment is rarely researched. This invisibility in the literature is echoed in the exclusion of older deafblind people in international development programmes (World Federation of the Deafblind, 2018). For example, there are only limited references to deafblindness in both the *United Convention on the Rights of Persons with Disabilities* and the WHO *World Report on Disability* (World Health Organization, 2011). Simcock and Wittich (2019) observe that in the UNCRPD particularly, these references largely focus on children.

Older deafblind people face various barriers to participation in research (Jaiswal et al., 2018; Roy, McVilly, & Crisp, 2018; Skilton, Boswell, Prince, Francome-Wood, & Moosajee, 2018) resulting in the ongoing absence of their voices in mainstream gerontological literature. However, for those ageing with deafblindness, invisibility is also apparent in the 'ageing with' literature. Identifying the key physical and sensory disabilities with which people may age in a chapter on 'ageing with impairment', Westwood and Carey (2018) only list the two single sensory impairments (visual impairment and hearing impairment) and omit deafblindness. Furthermore, in a later discussion about the experiences of those ageing with deafblindness in long-term care settings such as nursing homes, they erroneously support the points made with reference to a study concerning those with late-life acquired deafblindness, which specific- ally excluded those who age with the impairment (see Roets-Merken et al., 2017). In the 'deafblindness literature', Simcock (2017) argues that there is an inherent assumption that 'older deafblind people' are those who have acquired the impairment in later life, noting the broad titles of numerous journal art- icles that focus exclusively on the late-life acquired population. While in some articles clarity on the population is offered in the abstract or introduction, in others it is merely implied. Simcock (2017) also highlights the exclusion or limited inclusion of older people from research on the experiences of those living with deafblindness (see, for example, Ellis & Hodges, 2013; Kyle & Barnett, 2012; Oleson & Jansbøl, 2005), and limited coverage of the experience of ageing and old age in the autobiographical accounts, which tend to focus on experiences earlier in life, such as education and adolescence (see, for example, Coker, 1995; Murphy, 1991).

Such invisibility may partly be explained by the 'ageing with deafblindness' population's highlighting a key distinction drawn in deafblind research, policy, and practice: that between congenital impairment and acquired impairment (Dalby et al., 2009). Complexity in describing deafblindness was noted in the introduction to this chapter. In seeking to add clarity to descriptions of deafblindness and its effects, Dammeyer (2014) observes the long-standing classification of the impairment into either the congenital or acquired category by the research, policy, and practice communities. Notable differences in experiences and needs between these groups are confirmed in the literature (Dalby et al., 2009). For example, there is wide variation in the communication methods used by those in each category (Dalby et al., 2009) and while communication poses difficulties for all deafblind people, it can prove uniquely challenging for congenitally deafblind people, who may experience difficulty understanding the very concept of language (Hart, 2008). It is interesting to note that the relatively new *Journal of Deafblind Studies on Communication* focuses almost solely on communication among congenitally deafblind people.

Although the distinction can be helpful therefore, those ageing with deafblindness include people across this divide. For example, the population comprises of those ageing with congenital conditions, such as congenital rubella syndrome, but also those for whom one impairment is congenital and one acquired in childhood or early adulthood, and those for whom both impairments are acquired in

childhood or early adulthood (Wittich & Simcock, 2019). It also includes those with a congenital condition that results in acquired deafblindness, such as Usher Syndrome. The participants in Simcock's (2020) study illustrate this diversity, although they are all considered to be ageing with deafblindness (*n* = 8): one had congenital deafblindness; one had congenital deafblindness with subsequent trauma resulting in further sight loss; two had congenital profound deafness and acquired sight loss in childhood; three had congenital hearing impairment and acquired sight loss in early adulthood; and one acquired both visual and hearing impairment in early adulthood. The congenital: versus acquired distinction is therefore overly simplistic (Wittich & Simcock, 2019) and arguably artificial (Clark, 2014; Moller, 2003). In developing an approach to the description and classification of deafblindness, Ask Larsen and Damen (2014) have thus added, *inter alia*, the onset of each impairment relative to chronological age. However, arguably, it is the ageing with deafblindness population that specifically highlight the inad- equacy of this long-standing distinction.

Multiple Changes, Constant Adjustment

Experiences of multiple changes are commonly reported among people ageing with deafblindness (Gullacksen, Göransson, Rönnblom, Koppen, & Jørgensen, 2011; LeJeune, 2010; Oleson & Jansbøl, 2005; Spring, Adler, & Wohlgensinger, 2012), challenging the description of sensory impairments as 'stable' conditions (see, for example, Kelley-Moore, 2010; Shakespeare & Watson, 2001). When ageing with disability, changes in impairment occur concurrently with changes associated with ageing (Westwood & Carey, 2018) and such phenomena are observed among deafblind people (Simcock, 2017). This includes deterioration in hearing and vision, which may be associated with late manifestations of the original aetiology (Laustrup, 2004), the development of additional age-related sensory impairment (Wittich et al., 2012) or indeed both (Barr, 1990). Trauma in childhood or adulthood may also impact on any residual hearing or vision; for example, a participant with congenital deafblindness in Simcock's doctoral study was involved in an accident in early adulthood, which damaged the residual vision left in one eye. Gullacksen et al. (2011) note the increased risk of other physical health problems among congenitally deafblind people as they age; this may include further deterioration in proprioceptive function, as a result of changes in the peripheral and central nervous system (Goble, Coxon, Wenderoth, Van Impe, & Swinnen, 2009).

Changes are not restricted to those of a physical nature. Those ageing with deafblindness have had a life of reduced access to information, communication difficulty and potentially, high levels of social isolation (Gullacksen et al., 2011) and therefore may face old age with a sense of uncertainty (Simcock, 2017). Changes in social networks and loss of friendships and relationships, particularly with those able to use appropriate communication methods, have also been reported (Simcock, 2017). Such changes are largely related to the ageing process, but the associated effects are complicated by the existing deafblindness. Change in employment status, particularly the need for early retirement, was a shared experience for participants in Simcock's doctoral research (Simcock, 2020). It appears that this is common event for both deafblind people (World Federation of the Deafblind, 2018) and those ageing with other impairments (Westwood & Carey, 2018), resulting in the risk of both financial and social disadvantage. Verbrugge, Latham, and Clarke (2017) maintain that those with impairments may experience such changes associated with ageing sooner; a phenomenon termed 'accelerated ageing'. In her personal account of ageing with Usher syndrome, Stiefel (1991) describes many of her experiences as 'accelerated ageing' and Laustrup (2004) similarly observes early manifestations of ordinarily age-related change in data on deafblind adults with congenital rubella syndrome.

Responding to the various life changes experienced, those ageing with deafblindness report having to make adjustments (Simcock, 2017); the nature of these is described as 'multiple' (Miner, 1995), 'repeated and ongoing' (Göransson, 2008; Gullacksen et al., 2011), and 'constant' (Duncan, Prickett, Finkelstein, Vernon, & Hollingsworth, 1988). Westwood and Carey (2018, p. 229) note that people living with impairments 'lose many of the gains they achieved in rehabilitation' as they age. This experience is

evident in the ageing with deafblindness population (Göransson, 2008), particularly in relation to communication and the need to learn new methods of communication over the lifecourse (Erber & Scherer, 1999; Simcock, 2017). For example, age-related reduced sensitivity in the fingers can impact on the accessibility of tactile reading and writing systems such as braille, which may have previously been a format used to access information (Yoken, 1979). For some people ageing with deafblindness, living with the impairment for a long time renders such adjustments easier to manage (Bejsnap, 2004; Yoken, 1979). Nevertheless, for others, such adjustments are not experienced as easier, but rather reported as becoming harder or perceived as such, as the ageing process and impairment combine (Butler, 2004; Damen et al., 2005; Stiefel, 1991), as illustrated by the following:

> [A]t the age of 68, I contemplate the future with trepidation. There will be further transitions. They will be harder
>
> *Pollington, 2008, p. 33*

> Now that I'm of retirement age, the difficulties are closing in71-year-old contributor in
>
> *Stoffel, 2012, pp. 201–202*

Westwood and Carey (2018) argue that research involving those ageing with impairments can enhance our knowledge about resilience and positive adaptation, and our understanding of ageing with deafblindness is impoverished if the positive changes reported are not considered. Some people ageing with the impairment report on improvements in their hearing and/or vision, owing to either changes in their condition or medical intervention (Ellis & Hodges, 2013; Stoffel, 2012; Yoken, 1979). This includes those ageing with congenital deafblindness; for example, one participant in Simcock's study (*forthcoming*) describes his latest hearing aids as being 'brilliant' and comments that since having them, while 'I still don't hear everything… it is not a problem'. Others ageing with deafblindness describe their active engagement with rehabilitation services and enjoying the opportunity to learn new skills, even in much later life (Bejsnap, 2004; Duncan et al., 1988; Jenson & Christiansen, 2011; Pollington, 2008; Schoone & Snelting, 2011; Stoffel, 2012). An experience noted in Pollington's (2008) personal account is the ability to 'merge into the background' as she gets older, particularly as acquired deafblindness is common in later life (Wittich & Simcock, 2019). Now as an older person, one partici- pant in Simcock's study (*forthcoming*) jovially describes no longer being the only one of her family to have sensory loss, now that they have all aged: in the words of Pollington (2008, p. 33), for those with impairments, '[a]geing is a leveller'.

Unmet Needs and the Misrecognition of Deafblindness

Westwood and Carey (2018) maintain that an under-developed understanding of the features of ageing with impairment results in the marginalisation of disabled people in ageing policy. While the World Federation of the Deafblind (2018) argue that all deafblind people are at risk of exclusion from national and international welfare policies and development programmes, Simcock & Wittich (2019) contend that those ageing with the impairment are particularly overlooked. However, Westwood and Carey (2018) also maintain that health and social care services are ill-equipped to meet the needs of disabled people in later life, noting that disability organisations are not always able to respond to 'ageing issues', while services for older people often fail to respond to disability related matters. This latter point is illustrated by the observation that the human rights campaigning of organisations for older people has not engaged explicitly with disability rights (Phillips, Ajrouch, & Hillcoat-Nalletamby, 2010). Those ageing with deafblindness are reported to have expressed concerns about the ability of deafblind organisations to meet their needs as older people, and mainstream older people's services' ability to meet their needs as deafblind adults (Simcock, 2017). For example, those living in mainstream older people's accommodation-based care settings describe experiences of unmet need, especially in relation to social

inclusion (Göransson, 2008; Spring et al., 2012; Stoffel, 2012). Isolation in mainstream older people's services is not simply a consequence of health and social care staff lacking the relevant knowledge and skills, but also an outcome of being the only deafblind person in the setting, particularly where the deafblind person uses sign language (visually or tactually).

Westwood and Carey (2018, p. 234) also observe that health and social care systems are often designed around 'individual diseases rather than conditions involving multimodality'. Participants in LeJeune's (2010) qualitative study of the experiences of those acquiring a second sensory impairment, in addition to a pre-existing one, report on the inadequacies of single sensory impairment services in meeting their needs. While the experience of comorbid physical and mental health problems among deafblind people has been demonstrated (Bodsworth et al., 2011; Tiwana et al., 2016; Wahlqvist, Möller, Möller, & Danermark, 2013, Wahlqvist, Möller, Möller, & Danermark, 2016), Miner (1995) points out that for those ageing with deafblindness, a life of reduced access to information can result in limited awareness of the healthcare services available for older people.

The World Federation of the Deafblind (2018) reports that from the data available, only 37% of countries ($n = 50$) recognise deafblindness as a distinct disability. Feeling that one's needs or situation have not been recognised or have been misrecognised was a key experience among participants in Simcock's (2020) research, and contributed to their feelings of vulnerability, as the following examples illustrate:

> I knew I was getting in the way, and I just felt quite vulnerable at that particular moment, I, I didn't really know what to do… I don't know what other people thought of me. 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 (52-year-old with Usher Syndrome Type II).
>
> They (Healthcare Workers) often don't know about what's going on with deafblind people, so you have to plan every stage…. You have to give them information, information, tell them all. It takes lots of energy, lots of energy, explaining again and again and again… if you don't have a plan, you get a bit lost really (73-year-old with Usher Syndrome Type I: English inter- pretation of original contribution given in British Sign Language).

Although a lack of recognition and a paucity of research have resulted in those ageing with deaf blindness being *de facto* excluded from welfare policies and development programmes, the tendency of national and international policy on old age to homogenise the ageing experience (Lloyd-Sherlock, 2002; Walker, 2017) also contributes to their invisibility. The need to develop our understanding of the specific needs and experiences this sub-group of the deaf blind population, through their increased involvement in deaf blind research and mainstream gerontological study, therefore appears evi- dent. Nevertheless, writing from a social model of disability perspective, Oliver (2013, p. 1026) warns against emphasising differences between diverse sub-groups of disabled people, arguing it to be 'impotent in protecting disabled people, [their] benefits and services'. He maintains that such approaches depoliticise the social model, focusing on individual impairment and difference, rather than disabling barriers, which are then used in government policy to ration welfare, care and support. Furthermore, while change and consequent adaptation are common experiences of the ageing with deaf blindness population, it can be similarly argued that a model of individual adjustment is an inadequate interpretative tool for understanding the experience. Using the example of communi- cation method adaptations by those ageing with the impairment, Hersh (2013) observes that the corresponding need for communication partners to adapt to such changes is not always acknowledged or explored in the literature. The 'life adjustment model' adopted by Gullacksen et al. (2011) in their exploration of the experiences of deaf blind people over the lifecourse more clearly acknowledges the need for the social environment and service providers to adjust as those with deaf blindness age.

Next Steps and New Directions

There are clear knowledge gaps about people ageing with impairments (National Institute for Health and Care Excellence, 2015) and there have been associated calls for both further research and the inclu- sion of those ageing with disability to be involved in the co-production of knowledge (Westwood & Carey, 2018). Establishing the size of the ageing with deafblindness population locally and nationally is an important next step in increasing their visibility and informing resource allocation and health and social care service planning. Such data could also be useful in developing understandings about the importance of social and cultural contexts. Nevertheless, observing a paucity of good practice guidance for the involvement of all deafblind people in research and policy development (Jaiswal et al., 2018; Roy et al., 2018), establishing effective research and consultation approaches to secure meaningful participation is also a priority. Such approaches can inform much needed further qualitative inquiry into the experiences of those ageing with deafblindness to improve practice effectiveness. In enab- ling the accurate synthesis of research knowledge, study authors must make explicit the specific sub- group of the deafblind population concerned; in relation to particular sub-groups of those ageing with deafblindness, there have been specific calls for further research into the clinical needs of those ageing with congenital rubella syndrome and those with Usher syndrome (Armstrong & O'Donnell, 2004; Dalby et al., 2009; Ellis & Hodges, 2013).

In considering the maintenance of independence for those ageing with impairment, Agree (2014) proposes further exploration of the potential of assistive technologies. Wittich et al. (2016) identify improved assistive technologies as a priority for both the rehabilitation and research communities in the deafblind field, and some older deafblind people have expressed a desire to learn how to use new assistive technologies (Stoffel, 2012). However, those ageing with deafblindness have commented on the lack of available information about assistive technologies (LeJeune, 2010), and the difficulties using such devices owing to age-related changes such as reduced fine motor skills (Cohn, 1998; Göransson, 2008). It is therefore imperative that future research and development involves the 'ageing with' population.

The need for further research to inform, increase competence and capacity in both the policy and practice communities in the deafblind field and more widely is evident. Indeed, allied health and social care professionals working with older people have reported a lack of expertise in relation to supporting those with sensory impairment (Wittich & Simcock, 2019) and this probably extends to wider prac- titioner groups. Developing our understanding of the experiences and needs of people ageing with deafblindness requires collaboration between researchers and research stakeholders in both the con- genital impairment and acquired impairment fields: it is time for deafblind researchers, advocacy and disability groups, policy makers, and practitioners to bridge this long-standing divide.

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