# Chapter 28

# Aging and Combined Vision and Hearing Loss

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The problems of deafness are deeper and more complex, if not more important, than those of blindness. Deafness is a much worse misfortune. For it means the loss of the most vital stimulus — the sound of the voice that brings language, sets thoughts astir and keeps us in the intellectual company of man.

Helen Keller (1933) in *Helen Keller in Scotland: a personal record written by herself*

**Abstract**

This chapter begins with an overview of the current definitions of deafblindness, dual sensory Impairment, and combined vision and hearing loss, followed by a review of the literature on prevalence data, with a particular focus on older people across different geographic locations and sub-populations. The third section centers on aetiology, noting both congenital and acquired conditions, and their development throughout the lifespan. We provide a succinct history of deafblindness research as a relatively young field, and then address the various categories of deafblind people, briefly highlighting the policy and campaigning organisations that champion them. Next, we review the psychosocial impact of deafblindness on older people, highlighting key issues from the perspectives of both those affected as well as the professionals that work with them. This section includes the priorities of older adults and how these link to the current development or offer of relevant services. Finally, the chapter concludes with a view of the future of deafblindness rehabilitation for older adults. Noting important gaps in the literature, we outline priorities for the research, policy and practice communities, and offer recommendations for further reading and current opportunities of investigation.

**Introduction**

Any discussion of aging with a visual impairment would be incomplete without placing it in context of one of its common co-morbidities: hearing loss. This chapter begins with a description of the various current definitions and nomenclature of deafblindness /dual sensory impairment and how these relate to older individuals with combined vision and hearing loss. The next section reviews the literature on prevalence & incidence, with a particular focus on older people, across different geographic locations, as well as different sub-populations. The third section focuses on aetiology, though noting both congenital and acquired conditions, and their development throughout the lifespan, followed by a brief overview of the history of deafblindness research. It then reviews the psychosocial impact of deafblindness on older people, and includes the priorities of older adults and how these link to the current development or offer of relevant services. Finally, the chapter concludes with a view of the future of deafblindness rehabilitation for older adults, and important gaps in the literature, outlining priorities for the research, policy and practice communities.

**Definitions and Nomenclature of Deafblindness / Dual Sensory Impairment / Combined vision and hearing loss**

Terminology in the field of combined vision and hearing loss remains complex and confusing, in part due to several historical, clinical and inter-professional reasons. Historically, the terms *deaf* and *blind* were combined and hyphenated when referring to individuals that had both sensory impairments; however, the non-hyphenated term *deafblind* was then proposed in order to reflect the unique properties of the combined impairment, not just the addition of one and the other (Lagati, 1995). The umbrella use of *deafblindness* in the clinical, service and rehabilitation context implies two interesting restrictions, whereby professionals assume that the sensory impairments are more severe (e.g., total absence of vision and hearing) and that the population described is made up of children or individuals with congenital impairment (Wittich et al, 2013). Meanwhile, non-clinical stakeholders, such as researchers or administrators reported that they lean towards the use of the term dual sensory impairment, which softens the description of this population and is potentially more inclusive, specifically when communication with and about older adults with acquired sensory loss, who neither identify with nor want to seek services for blind and deaf individuals.

The classification and its terminology have been well described in its complexity by Dammeyer (2014) who breaks down the population categories based on whether each impairment is congenital or acquired, or each ranging from mild to total. Ask Larsen and Damen (2014) took this approach further in the context of congenital aetiology, adding the dimensions of diagnostic/medical definitions, whether onset time preceded the development of communication abilities, and ability as it relates to mobility and access to information, as well as onset order relative to chronological age. Such work develops the earlier identification of four distinct groups of deafblind people (Deafblind Services Liaison Group, 1988), which also considered the timing and order of onset of each impairment. The United Kingdom Department of Health (1997), in their good practice guidelines for health and social care services, added a fifth distinct group and applied the classifications specifically to older deafblind people: (1) those whose deafblindness has been acquired and developed in old age; (2) older people who have lived with sight impairment and subsequently acquire a hearing loss; (3) older deafened or hearing impaired people who have used speech to communicate, who subsequently acquire visual impairment; (4) older culturally Deaf people who use Sign Language, who subsequently acquire visual impairment; and (5) older people who have been deafblind for all or the majority of their life. The majority of deafblind people fall into the first of these groups.

In the context of the present chapter, this large variety and variability among terms and dimensions provides both a challenge and an opportunity because older adults with combined vision and hearing loss may be part of any and all these groups described above. Therefore, for the sake of continuity and simplicity within this chapter, we largely utilize the term *deafblindness* when referring to this population, independently of when or how the sensory losses occurred or how severe they are. We do, however, want to highlight that the great variability within this population is reflected in the great variability of their unique and specific needs, even though a single label may give the impression that this population is easily summarized within one term (Simcock, 2017b).

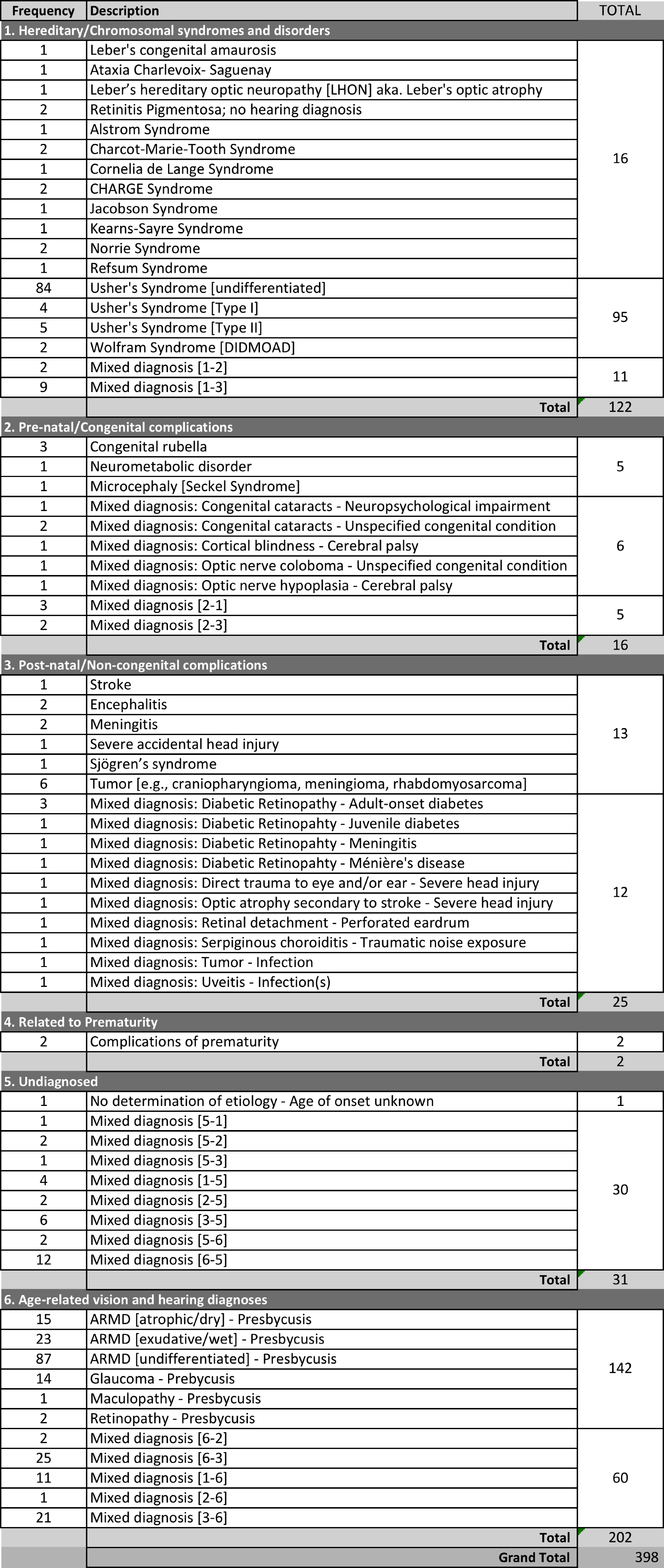
**Prevalence & Incidence**

Obtaining accurate estimates of deafblindness prevalence is important in order to plan the allocation of resources, the education and preparation of the next generation of health and social care professionals, as well as the initiation of efforts for prevention, detection, treatment and rehabilitation. However, determining deafblindness prevalence is challenging because of the lack of a consistent definition for the phenomenon, limitations inherent to self-reported assessments of impairment, disability or handicap, in addition to communication difficulties in completing formal assessments, and the comparatively small size of the population. Several efforts have been made to estimate the prevalence of age-related or acquired deafblindness, with specific focus on sub-groups such as community-dwelling older individuals (Keller et al, 1999; Chia et al, 2006; Bazargan et al, 2001), those with intellectual disabilities (Evenhuis et al, 2001), those hospitalized for hip fractures (Lieberman et al, 2004; Grue et al, 2009), veterans (Smith et al, 2008; Lew et al, 2011), seniors receiving nursing-home or long-term care (Guthrie et al, 2016; Yamada et al, 2015; Guthrie et al, 2018), as well as participants in large population-based epidemiological studies (Dawes et al, 2014; Kwon et al, 2015; Gopinath et al, 2013; Parfyonov et al, 2016). The overall consensus is that the prevalence of deafblindness increases with increasing age, and that great variability exists in prevalence among the sub-groups. For example, using objective measures of vision and hearing, the proportion of older individuals with deafblindness has been reported as high as 20% in residential care or day centres (Roets-Merken et al, 2014) and up to 30.1% in hip fracture patients (Grue et al, 2009). When using subjective questionnaire measures of sensory loss, estimates have been as high as 26% in nursing home residents (Yamada et al, 2015), 22%, 33.9% in long-term care residents (Guthrie et al, 2016), and 37.6% among centenarians (Cimarolli and Jopp, 2014).

Estimates of the number of older people with congenital or early-onset deafblindness are not currently available. The closest approximations come from studies that describe specific deafblind populations, such as a study from Denmark that reported that nine of their 190 congenitally deafblind participants (4.7%) were over the age of 60 (Dammeyer, 2010). Similarly, the portrait of the deafblindness rehabilitation population in Montreal, Canada (Wittich et al, 2012) described that 69% of individuals receiving rehabilitation services for combined vision and hearing loss were reported to be over the age of 64; at the same time, within that the same population, 49% were categorized as having a diagnosis of any age-related or adult-onset sensory condition. These numbers indicate that 20% of the older adults in this population were receiving services for the rehabilitation of congenital or progressive illnesses, such as Usher Syndrome or more rare conditions such as Charcot-Marie-Tooth syndrome (Evers et al, 2012). One methodological challenge in interpreting these large differences may lie in differences in how congenital deafblindness is defined, reflecting what is perhaps an artificial distinction between congenital and acquired deafblindness (Möller, 2003), and whether individuals with Usher Syndrome are included in such groupings or not. Arguably, Usher Syndrome is a *congenital* condition resulting in *acquired* deafblindness. In the Montreal sample, this population is likely larger than elsewhere, given a reported Founder effect in the French-Canadian population (Ebermann et al, 2007). Incidence of deafblindness among older adults has only been examined in one population-based study (Schneider et al, 2012) which reported that, over a period of 5 years, there was a 1.6% incidence among individuals without sensory impairment, and a 11.3% incidence among those already affected with one sensory impairment. However, the authors mention that power was low to identify specific risk factors due to survivor bias and the small sample that progressed to deafblindness within the study period.

**Aetiology**

This brings us to some of the most prevalent causes of deafblindness, an impairment known to have a ‘range of aetiologies’ (Bodsworth et al, 2011). This range may be best demonstrated in Table 1 which provides diagnostic groupings and frequency counts for the data published by Wittich et al, (2012). It does not come as a surprise that one third on individuals were diagnosed with the two most common age-related sensory impairments, namely age-related macular degeneration and presbycusis, affecting vision and hearing respectively. It becomes apparent that most age-related/acquired causes for vision loss (e.g., glaucoma or diabetic retinopathy) are independent of those causes reported for hearing loss (e.g., noise exposure), except that each of their prevalence increases with increasing age. Another noteworthy complexity is the variability of combinations whereby one impairment may be acquired, whereas the other may be congenital. What complicates the picture further is that some of the diagnostic categories are associated with limited life span (e.g., Alstrom syndrome, CHARGE Syndrome, or Kearns-Sayre Syndrome) whereas other are not (e.g., Marie-Charcot-Tooth syndrome); therefore, older adults with deafblindness are an extremely heterogeneous population as some of them have simply aged with a congenital condition. Similarly, Dammeyer (2010) provided a detailed description of aetiologies of congenital deafblindness, where the most frequent causes among those that lived into adulthood included Rubella (28.3%), Down syndrome (7.9%) and complications related to prematurity (7.1%), in addition to 24.4% whose aetiologies were undetermined or unknown. Even though their sample age extended all the way to 80 years, a breakdown of aetiology for older adults was not available.



**History of Deafblindness Research**

The origins of deafblindness campaigning organisations are often found in shared concern about the needs of deafblind children. ‘Deafblind International’, an international, not-for-profit membership organisation working to promote awareness of deafblindness and to influence appropriate service development globally, began its life in the 1950s as the *International Association for the Education of Deaf-Blind* (http://www.deafblindinternational.org/). At this time, its work centred on improving education for deafblind children. The UK charitable organisation *Sense* also began in the 1950s, with the campaigning work of ten families of children with congenital rubella syndrome. Similarly, the research community initially focused on deafblind children and their educational and rehabilitation needs (Wittich, Jarry, et al, 2016). It was not until the 1980s that organisations became explicitly concerned with the needs of other groups of deafblind people. In particular, Wittich et al, (Wittich, Jarry, et al, 2016) note emerging consideration of the rehabilitation needs of older people with acquired deafblindness. This decade also saw a broadening of the age range of deafblind persons included in research activity. Much of this work was undertaken in the USA (Rönnberg and Borg, 2001), following amendments to the Rehabilitation Act 1973, which increased the mandate of the newly created National Institute of Handicapped Research (Wittich et al, 2016). A 2001 review of the behavioural and communicative research on deafblind individuals during the 1980s and 90s, highlighted increased inclusion of diverse sub-groups of deafblind people in research activity (Rönnberg and Borg, 2001). However, the authors noted that ‘[f]rom an international perspective, the population of deafblind [had] received little research attention’ (p74). They go on to critique some of the included studies for failing to make explicit the particular sub-group of deafblind people under investigation. As a highly heterogeneous population, such omission has resulted in limited generalizability and difficulties in synthesising research findings; Dammeyer (2015) argues that this is one of the reasons for research in deafblindness remaining in its infancy, and calls on researchers to offer thorough definitions of the study population concerned.

As a result of changes in the demographic profile in developed countries, research into the needs of those with late life acquired deafblindness has however increased and gained visibility. A systematic review of the literature on comorbidities and outcomes associated with deafblindness in older adults (Heine and Browning 2015) identified 42 papers concerned with this population. The papers report on research adopting a range of methodologies, including cross-sectional design and longitudinal studies, and the reviewers note the use of varying methods of vision and hearing assessment and a variety of terminology for deafblindness in this work. Such variation was also observed in Tiwana et al’s (2016) systematic review of the impact of acquired deafblindness on everyday competence; the reviewers note how this problematizes attempts to draw conclusions from the body of research.

While research on late life acquired deafblindness has increased, there is a dearth of research on older people who have aged with deafblindness. This reflects the observation of Grassman and colleagues (2012) that little is known about the experiences of people ageing with a range of impairments. Though these are a much smaller sub-population of older deafblind people than those with late life acquired deafblindness, the need for further research has been noted (Simcock, 2017a). There have been calls for further study on changing clinical needs (Dalby et al, 2009) and those of specific groups, for example, individuals those born with congenital rubella syndrome during the 1960s rubella pandemic (Armstrong and O’Donnell, 2004) and those with Usher syndrome (Miner, 1995; Damen et al, 2005). Themes identified in a 2016 systematic review of the experiences of those ageing with deafblindness (Simcock, 2017a) were similar to those of adults ageing with other impairments: on-going change and the resultant need for enduring adaptation; a particular relationship between ageing and impairment, with one exacerbating the other; a sense that whilst one can learn adaptive strategies having lived with impairment for a long time, it does not necessarily get easier. However, just as Heine and Browning (2015) and Tiwana *et al,* (2016) observe, Simcock (2017a) notes that both definitional variation and a failure of study authors to offer clarity in reporting on the particular deafblind population concerned, rendered synthesis of the identified material problematic.

**The Psycho-Social Impact of Deafblindness on Older People**

Our understanding of the psychosocial impact of deafblindness on older people is adversely affected by the paucity of research on the consequences of the impairment (Brennan and Bally, 2007). Schneider et al (2011) observe inconclusive findings relating to the presence of and nature of any additional or interactive impact of dual over single sensory impairment, albeit that ‘intuitively [deafblindness] may be expected to have additional impacts’ (p. 1319). This has implications for future research priorities, which are considered later in this chapter. However, studies have identified various psychosocial consequences, which have been described as both serious (Heine and Browning, 2004) and wide-ranging (Brennan and Bally, 2007) and have the potential to impact on individuals’ well-being (Dean et al, 2017).

Although they are a highly heterogeneous population, what deafblind people have in common is deprivation in use of the distance senses (sight and sound) (McInnes, 1999), resulting in difficulties with communication, accessing information, and mobility (Department of Health, 1997). There is a recognised link between sensory impairment and communication difficulties (Heine and Browning, 2004); Erber and Scherer (1999) highlight that such difficulties can be severe and, for older people, are often complicated by co-morbidities common in later life such as dysarthria, depression, and cognitive impairment. Responding to the limited evidence on the experience of communicative challenges associated with dual sensory loss, Heine and Browning (2004) undertook a systematic study involving in-depth qualitative interviews with ten older adults with sensory loss , four of whom had deafblindness. Participants reported frequent episodes of ‘communication breakdown’, particularly in social and other group situations; these breakdowns often resulted in embarrassment, anxiety and fatigue. In their secondary analysis of two large datasets and case studies of 20 older adults with acquired deafblindness, Pavey et al (2009), similarly found communication difficulties to be ‘an extremely strong theme to emerge from the research’. Participants reported feeling socially isolated, in part as a result of communication difficulties. The experience of social isolation amongst older deafblind people is noted elsewhere in the literature (see for example Bodsworth et al, 2011; Schneider et al, 2011; Göransson, 2008; Cook et al, 2006; LeJeune et al, 2003) and as such, on-going human contact has been recommended in order to sustain the psychosocial wellbeing of this population (Erber and Scherer, 1999). Nonetheless, in their UK based study of the experiences of deafblind people using British Sign Language, Kyle and Barnett (2012) highlight that participants did not describe high levels of social isolation. However, as the authors acknowledge, participants in this study were ‘more confident’, ‘already in contact with organisations’ and ‘those who have friends who were also Deafblind’ (Kyle and Barnett, 2012, p. 42). Furthermore, no participants over the age of 65 were recruited, and all participants identified as members of the Deaf community. These contrasting findings are illustrative of diverse experiences and differing psychosocial needs among the heterogeneous deafblind population.

While communication difficulties may result in diminished psychosocial well-being for some older deafblind people (Erber and Scherer, 1999), reflecting earlier research, Heine and Browning (2004) observed that their participants developed and adopted their own strategies for managing communication breakdown. Such strategies often involve making adjustments to communication methods and techniques; indeed, some older deafblind people have described how they have needed to learn new methods of communication over their entire life course (Gullacksen et al, 2011; Göransson, 2008; Spring et al, 2012). This need may be associated with changes in residual hearing and vision or other age-related physical changes (Damen et al, 2005; Yoken, 1979; Oleson and Jansbøl, 2005). However, while communication training programmes have been recommended for both older deafblind people and their communication partners (Heine et al, 2002), Hersh (2013b) notes that the corresponding need for communication partners to adapt to such changes is not always acknowledged or explored in the literature; this impacts on our understanding of the psychosocial impact of communication difficulties associated with deafblindness.

Although sensory impairments have been described as ‘stable’ conditions (Kelley-Moore, 2010; Shakespeare and Watson, 2001), older deafblind people report experiencing changes in both their hearing and vision in a number of studies (see for example Göransson, 2008; LeJeune, 2010; Gullacksen et al, 2011; Oleson and Jansbøl, 2005) and in personal accounts (See for example Pollington, 2008; Stiefel, 1991; Stoffel, 2012; Yoken, 1979). For those deafblind as a result of Usher Syndrome, changes in vision in particular are noted, owing to the nature of retinitis pigmentosa progression (Damen et al, 2005; Miner, 1997; Miner, 1995). One reported consequence of such physical change is the need to make adjustments, particularly adjustment to progressive loss (Brennan and Bally, 2007), albeit that these changes are not always deteriorative in nature (Stoffel, 2012). Brennan and Bally (2007) observe that for many older people, loss of vision and hearing occurs alongside other losses or disengagements, such as retirement, widowhood and reduced social networks, impacting on the process of adaptation. Older people experience both physical and environmental change (Heine & Browning 2004; Göransson 2008) and a model of individual adjustment is therefore inadequate as an interpretative model. Göransson (2008) and Gullacksen *et al* (2011) adopt a ‘life adjustment model’ to interpret their interview and focus group data. This model acknowledges that adjustment is not just an individual response to impairment, but that people also need the social environment and service providers to adjust as they age.

It is not just those with late life acquired deafblindness that experience such changes in hearing and vision. A survey collecting information on the ageing process completed by 58 congenitally deafblind adults in Denmark identified that some of these changes resulted from the original aetiology of deafblindness and their potential late manifestations; others were attributed to other disorders, including age-related conditions (Laustrup, 2004). Similarly, older adults who have aged with deafblindness are reported to experience the need to make a range of consequent adjustments (Simcock 2017a). This appears to support the conclusion of Göransson (2008) that ‘deafblindness can never be regarded as something static’ (p. 16), irrespective of the age and timing of onset of the impairment.

Several studies report that single sensory impairment adversely impacts on the everyday competence and independence of older people (Lupsakko et al, 2002; Tiwana et al, 2016). Conversely, much less is known about how late life acquired deafblindness affects such ‘everyday competence’, defined as the ability to complete both activities of daily living (ADL) and instrumental activities of daily living (IADL) (Lupsakko et al, 2002; Brennan et al, 2006; Tiwana et al, 2016; Roets-Merken et al, 2018). Even less is known about the impact of deafblindness on the independence of those ageing with the impairment, albeit that some older people report that living with deafblindness over a period of time does not make maintaining independence any easier (Damen et al, 2005; Simcock, 2017a).

A 2002 Finnish study found that older deafblind people had greater difficulty with ADL and IADL compared to those with either no or single sensory impairment (Lupsakko et al, 2002). Analysis of quantitative data in the UK identified that older deafblind people had increased difficulty with independent living skills; feelings of loss of independence were likewise evident in the qualitative data. In their systematic review exploring the impact of late life acquired deafblindness on everyday competence, Tiwana et al (2016) identified studies similarly reporting that the impairment adversely impacted on the ability to maintain independence (see, for example, Brennan et al, 2005; Harada et al, 2008; Grue et al, 2009). Tiwana et al (2016) also note that older people with deafblindness appear to have greater difficulty completing both ADL and IADL than those with single sensory loss. However, the authors highlight limitations of the studies included, such as varying definitions of deafblindness, reliance on self-reported sensory impairment, and small samples consisting of older people known to specialist organisations. Furthermore, older deafblind people may have additional age-related impairments and health problems that can impact on the maintenance of independence (Pavey et al, 2009) and Tiwana et al (2016) acknowledge that

[i]t may be difficult to tease out the role of sensory impairments, physical illnesses and advancing age when people have difficulties with everyday tasks in later life (p. 204).

There have therefore been calls for further research, including recommendations for more qualitative studies, to explore the experiences of older deafblind people in relation to everyday competence (Tiwana et al, 2016; Schneider et al, 2011).

The negative impact of single sensory impairment on older people’s quality of life has been observed in various studies (Tay et al, 2007; Bodsworth et al, 2011) and each impairment has been described as having a ‘unique detrimental effect’ (Heine and Browning, 2015). Less is known about the effect of deafblindness on quality of life (Bodsworth et al, 2011), though deafblind people have been observed as reporting reduced quality of life (Heine and Browning, 2014; Tseng et al, 2018). Brennan (2003) and Dean et al (2017) maintain that there is an increasing body of evidence that deafblindness has a negative impact on quality of life. Chia et al (2006) and Dean et al (2017) focus specifically on health-related quality of life (HRQOL) in their Australian and UK-based studies with deafblind people. Chia et al, (2006) observed that dual sensory impairment was associated with poorer HRQOL than single sensory loss; this association was evident irrespective of the aetiology of sensory impairment, and Dean et al (2017) undertook a survey-based study with 90 people with Usher Syndrome, identifying a link between psychosocial wellbeing and HRQOL.

In addition to reduced HRQOL, older people with deafblindness have self-reported poorer health (Crews et al, 2004; Tiwana et al, 2016). Congenitally deafblind people are identified as being at risk of further physical health problems in later life, in part owing to late manifestations of the original aetiology (Gullacksen et al, 2011). They have also been identified as being at greater risk than non-deafblind people of various emotional, psychological and mental health difficulties (Simcock, 2017a; Wickham, 2011), with higher risk of acute confusion in long-term residential care (Cacchione et al, 2003) and high levels of psychological distress (Pavey et al, 2009; Bodsworth et al, 2011). In their examination of delirium in older people admitted to a district hospital in the USA, George et al, (1997) observed significantly higher levels of dual sensory impairment in those admitted with the condition. While psychological assessment of deafblind people is complex (Bodsworth et al, 2011), such findings do suggest that those with dual sensory loss are at increased risk of emotional, psychological and mental health problems.

However, whether deafblind people are at greater risk than the general population is difficult to determine. For example, when considering the research relating to depression amongst deafblind people, both Chou (2008) and Hersh (2013b) highlight mixed findings. Studies adopting both self-reporting and objective measures of impairment and health status have noted greater frequency of depressive symptoms or increased risk of depression amongst deafblind people than those without the impairment, even after controlling other significant covariates for the condition (Schneider et al, 2011; Tiwana et al, 2016; Guthrie et al, 2016; Brennan and Bally, 2007; Han et al, 2018; Cosh et al, 2017). However, Lupsakko et al (2002) observed that whilst depressive symptoms were common in older deafblind people, major depression was not. Analysing data from the English Longitudinal Study of Ageing (ELSA), Chou (2008) observed that, once health indicators were controlled for, the association between deafblindness and depression was not maintained, whilst sight loss remained a clear predictor of depression. Volden and Saltnes (2010) note that depression amongst deafblind people may result from a number of complex, inter-related factors. For older deafblind people, the risk factors related to depression in later life, such as a move to residential care and increasing difficulty with ADL/IADL, may also be significant (Lupsakko et al, 2002; McDonnall, 2009).

Mixed findings are also evident in research on sensory loss and cognitive impairment (Tiwana et al, 2016). A Spanish study exploring the impact of deafblindness on cognition of older people found that those with deafblindness had poorer cognition than those single sensory impaired or with no sensory impairment (Vazquez et al, 2012). Similar to the Australian study of Gopinath et al, (2013) and the Icelandic study of Fisher et al, (2014), Guthrie et al, (2016; 2018) observed higher rates of cognitive impairment amongst older deafblind people. However, in their USA based quantitative study, Lin et al (2004) found that deafblindness doubled the risk of cognitive decline over a period of four years, when compared to no sensory impairment, but not when compared with vision impairment alone, which posed a comparable level of risk. Led by the University of Manchester, UK, the European *Sense Cog Project* (http://www.sense-cog.eu/) is seeking to develop our understanding of the relationship between age-related sensory impairment and cognitive and mental health functioning. A team of clinicians and researchers across Canada within Team 17 (Interventions at the Sensory-Cognitive Interface) of the Canadian Consortium on Neurodegeneration and Aging (http://ccna-ccnv.ca/en/) are undertaking a range of experimental studies and interventions, qualitative interviews and analyses of large databases such as the Canadian Longitudinal Study on Aging (https://www.clsa-elcv.ca/) to develop our understanding of the relationships between sensory and cognitive loss in older adults, specifically those who are at risk of dementia. Even though the assessment of dementia in the deafblind remains difficult (Bruhn and Dammeyer, 2018), such large-scale research projects will enhance our understanding and have the potential to inform interventions aimed at improving quality of life, care and support for the older deafblind population. Research-informed interventions are of particular importance in this context, as the risk of mental health difficulties amongst the deafblind population is exacerbated by the paucity of specialist services (Bodsworth et al, 2011; Wickham, 2011; Mar, 1993). The risk of misdiagnosis of mental health conditions, as a result of miscommunication or misinterpretation of the effects of deafblindness, has also been noted (Miner, 1997; Hersh, 2013a; Sauerburger, 1993).

The psychosocial consequences of deafblindness are not limited to the individual with the impairment. Lehane, and colleagues (2016) highlight that ‘[a]cquired sensory loss of one family member can have a significant impact on the well-being of the entire family, especially the spouse’ (p. 34). However, although the impact of an individual’s single sensory loss on their family has been extensively researched, Brennan and Bally (2007) maintain that much less is known about the impact of deafblindness on family members. Whilst literature reviews have reported on the adverse impact of single sensory loss on older couples’ psychosocial wellbeing (Lehane, Dammeyer, et al, 2016), Westaway et al, (2011) found no significant differences between spouses of people with deafblindness and those with single sensory impairment, in relation to depression levels or caregiver burden, a conclusion likely limited by their small sample size.

Responding to the dearth of literature on this topic, particularly in relation to sexuality, Lehane, Dammeyer, Hovaldt and Elsass (2017) undertook the first known study to examine older couples’ sexual activity where one spouse has acquired deafblindness. This survey-based study, adopting a cross-sectional design, involved 45 couples aged 50 years or over. Couples were asked about their sexual desire, sexual activity and satisfaction with their sex lives. Data identified reduced sexual activity amongst couples living with acquired deafblindness, which was associated with reduced desire and lower levels of sex life satisfaction. The study authors suggest therefore that ‘the experience of [acquired deafblindness] may have an impact on older couples’ sexual relationships’ (p. 9), and call on practitioners to pay careful attention to the importance of sexuality in their work with older deafblind people. A recent and, at the time of writing, on-going international online longitudinal study of couples’ experiences of sensory loss, named the *International Study of Support and Sensory Loss Project (Project ISSSL),* seeks to identify the most effective methods of support and coping for couples living with single and dual sensory loss; this study will further contribute to our understanding of the wider psychosocial impact of deafblindness.

**The Future of Deafblindness Rehabilitation and Research**

The current demographic trends are likely a driving force in how the field of deafblindness will develop over the coming decades (Christensen et al, 2009). In the demographic profile of deafblindness rehabilitation clients, Wittich and colleagues (2012) pointed out that the majority of service users in 2010 were over the age of 65, with over 43% being over 85, thereby representing the parents of the baby boomers. These proportions were similar to those reported in Denmark (Dammeyer 2013), and their distribution is a good indicator of likely research and service provision priorities. Potential future directions and current gaps have been described from three different perspectives: older adults with deafblindness themselves (LeJeune 2010), researchers working with this population (Saunders and Echt, 2007; Saunders and Echt, 2011) as well as their clinical service providers (Wittich, Jarry, et al, 2016).

The study by LeJeune (2010) provided particularly rich data because the sample that participated in the nine focus groups consisted of all possible members of the aging deafblind community, including those who grew old with congenital impairments, as well as those with one or both acquired sensory losses, and those that communicated either orally or via sign language [as an aside, the challenges of conducting focus groups with deafblind sign language users have been described elsewhere (Arndt, 2011) and are worth reflection]. LeJeune (2010) provided an insightful qualitative description of the client perspective on topics such as feeling abandoned by service delivery programs, because many professionals traditionally trained and working with one sensory impairment were overwhelmed and unqualified to provide their services when a second sensory loss was present. Clients reported a lack of available information about assistive devices, and saw this lack reflected in the knowledge of their service providers as well. For culturally Deaf individuals, acquired vision loss becomes a communication disorder in addition to the impairments that are traditionally associated with visual impairment, such as mobility constraints. Participants reported that they faced ageist stereotypes and needed to overcome preconceived perceptions about older adults using assistive technologies in the presence of sensory loss (also see Fraser et al, 2016; Hersh, 2013b). Many of these challenges made them concerned about their future, initiating psychosocial and psychological fears of loneliness, depression and isolation (Mick et al, 2018). Finally, finding herself separated from life through her sensory losses, one participant pointedly expressed her lack of cognitive stimulation with the statement “There is nothing to help my mind think” (LeJeune, 2010, p. 151), highlighting the possible effects of sensory deprivation.

From the perspective of clinical researchers in dual sensory impairment and aging, Saunders and Echt (2007) discussed research priorities. As far as service provision was concerned, they first pointed towards a need for training to detect acquired deafblindness and the development of screening tools that are suitable for older adults, an effort that is currently underway (McGilton et al, 2016; Wittich et al, 2018). Furthermore, they discussed the need for suitable and specific measurement techniques and tools because current evaluation and outcome measures in vision or hearing were designed for only one sensory impairment, not both. Since then, Dalby and colleagues (2009) have reported on the development of the Deafblind Supplement to the interRAI Community Health Assessment as an evaluation tool specifically designed for deafblindness (Hirdes et al, 2007); however, this supplement is linked to the administration of a detailed overall health assessment, and is not intended to be administered separately. Once deafblindness is detected, needs shift towards improved communication abilities between service providers and clients in order to ensure optimal adherence to treatment and intervention protocols. In the context of assistive technologies, the authors discussed three specific aspects of development priorities: improved communication, enhanced environmental awareness, as well as greater device usability. In the context of communication, the authors suggest increasing the combination of visual and auditory cues, in order provide redundancy to increase signal over noise. Environmental awareness could potentially be improved through the enhancement of localization cues, and the continued development of devices that are designed specifically for the deafblind (e.g. Vincent et al, 2014). Finally, Saunders and Echt (2007) suggested that interconnectivity of information may increase access of assistive technologies. Further, general accessibility and ergonomics will need to be improved; however, this direction of research has so far only received little attention (Wittich, Southall, et al, 2016; Evers et al, 2012).

When pooling opinions from clinical and rehabilitation service providers, Wittich and colleagues (Wittich, Jarry, et al, 2016) were able to separate which future directions were specific for rehabilitation versus research in deafblindness, and which overlapped. Common themes that have also been reflected in the previous work by LeJeune (2010) as well as Saunders and Echt (2007) included the need for improved assistive technologies, better communication services and strategies, as well as an overall more integrated interdisciplinary approach to this field. The results highlighted the importance of maximizing the use of the remaining sensory abilities, and the need to work collaboratively, in order to avoid isolation of professional expertise. With regard to unique research priorities, participants echoed the need for more specific measurement tools, especially those that could capture the clinical outcomes of rehabilitation interventions, in order to provide better evidence to guide practice. Finally, there was a call for more systematic data tracking (e.g., client registries for accurate incidence and prevalence reports) and cost analysis evaluation (e.g., for quantification of early intervention outcomes). This shift towards providing data likely reflects a transition of this field towards a domain rooted in strong evidence-base. All parties involved will need to contribute to this goal, including clinicians, health professionals, administrators and all other stakeholders.

**Conclusion**

Looking into the future of research in aging and deafblindness, one of the central challenges as well as opportunities is the need to consider the complexity and diversity of this population. The present chapter is a first attempt to combine knowledge and perspectives on aging with deafblindness across two main populations: those with congenital and those with acquired impairments. However, even this description is too simplified to do all our clients justice, given their heterogeneity. This diversity has other effects for our work, because the scientific literature is not centralized or easily accessible in one peer-reviewed journal, but widely distributed across many professional domains (Wittich et al, 2013). The *Journal of Deafblind Studies on Communication* (http://jdbsc.rug.nl/) has become a focal point for research in this field; however, the central topics focus on communication acquisition and development in congenitally deafblind children. There is currently no comparable journal in aging. Resource access has taken important steps forward through online tools such as the Swedish database containing over 3500 articles on deafblindness, hosted by the *Nationellt kunskapscenter för dövblindfrågor* (http://nkcdb.se/research-overview/, interface available in Swedish and English) as well as an on-line Community of Practice on Deafblindness, *La communauté de pratique en surdicécité,* in Canada (http://cdpsurdicecite.org/, interface available in French, translation into English is ongoing), and resources available through organizations such as the *Hellen Keller National Centre for Deaf-Blind Youths and Adults* (https://www.helenkeller.org/hknc). Still, challenges remain to elevate much of the available on-line information to a peer-reviewed level that can withstand the rigour of scientific standards.

One of the more philosophical challenges that remain to be investigated and validated in detail is the concept that deafblindness is a multiplicative impairment that goes beyond the addition of vision loss plus hearing loss, but creates a new and more severe entity because the absence of the second sense impairs the capacity to compensate. Luey (1994) describes how this phenomenon of “the combined loss of both hearing and vision creates a whole new world - muffled, blurred, and disorienting” (p. 213). Other authors such as Hersh (2013b) mention the additive or multiplicative effects of deafblindness in order to justify the complexity and severity of this impairment, but without further explanation or investigation of its multiplicative nature. Saunders and Echt (2012) took an important step when reviewing evidence spanning from the psychosocial effects and the functional limitations all the way to audio-visual integration and the neuroanatomical overlap between the two senses, demonstrating how the combined impairment (often) results in larger functional effects; however, these results are not always consistent and likely depend on the type of task or situation in which the measurements and observations are made. Establishing this “breaking point” where one sense cannot compensate for the other anymore is a challenge that continues to elude researchers.

The preparation of professionals working with the deafblind clientele (aging or otherwise) has been a point of discussion for some time (McInnes, 1999). More recently, other allied healthcare professions, such as occupational therapists, find themselves in need of training and expertise working with older adults that are affected by sensory impairment, but they find themselves lacking where their training is concerned (Wittich et al, 2015; Wittich et al, 2017). This interest reflects a general underlying need for more information about deafblindness in the context of aging, which is further reflected in the recent inclusion of a chapter on sensory factors relevant to the design of assistive technologies for older adults in a textbook on gerontechnology (Wittich and Gagné, 2016). There remain numerous opportunities to raise awareness about deafblindness, at the level of front-line health and social care, as well as further up in the hierarchy of health and social care administration and policy. Some researchers may shy away from deafblindness as an area of investigation because of the perception that this type of work may be loaded with methodological challenges, and potential difficulties in obtaining funding and producing high-impact publications; however, in the context of geriatrics and gerontology this could be said about many aspects of the study of aging. As our field moves forward, the need for complexity and a tolerance for uncertainty and variability is essential in order to understand a world layered in the same complexity as its research topics.

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