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Paula C. Fletcher

Wilfrid Laurier University, pletcher@wlu.ca

Dawn M. Guthrie

Wilfrid Laurier University, dguthrie@wlu.ca

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The Lived Experiences of Individuals with Acquired Deafblindness: Challenges and the Future

Paula C. Fletcher and Dawn M. Guthrie

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Abstract

The lived experiences of seven individuals who are deaf blind (DB) were explored through the use of semi-structured face-to-face interviews. Two of the emerging themes from this phenomenological analysis were: (1) the daily challenges faced by the participants (e.g., difficulties with communication; compromised activities of daily living; lack of independence; and (2) their lack of preparedness for the future resulting from the uncertainties associated with their degenerative diseases. The findings from this study clearly articulate the importance of intervenor services from the perspective of these individuals.

Introduction

According to Watters, Owen and Munroe (2005) deafblindness (DB) is "a condition, that combines any degree of hearing loss with any degree of vision loss that interferes with communicating and acquiring information, even though individuals who are deafblind may still have varying levels of useful vision and hearing." (16) Being deafblind is an impairment that is distinct from a single sensory loss since individuals with deafblindness are compromised in their ability to compensate for the loss of one sense with the other. This dual sensory loss (DSL) makes everyday tasks (e.g., mobility, communication) even more complicated than for individuals with a single sensory loss (Lewin-Leigh, 2007). As such, deafblindness needs to be considered as a unique condition that is distinct from the disability associated with only one of vision or hearing impairment.

Caban et al. (2005) estimate that 3.3% of Americans report having a concurrent visual and hearing impairment, with the highest prevalence rates being reported for those over the age of 79 (16.6%). The cause of DB varies in nature (e.g., congenital vs. acquired) and contributes to the heterogeneity of this group (see Munroe, 2001 for a thorough discussion on the causes of being DB). Much variability exists along the dual sensory impairment spectrum in terms of the functional, hearing and visual abilities that individuals who are DB possess (Ronnberg & Borg, 2002). Given the diversity of this group, ascertaining their unique individual needs is warranted (Dalby et al., 2009a).

Most of the literature concerning individuals who are DB focuses on the congenitally DB and DB children (Schneider, 2006). Previous research that is available concerning adults with DB tends to be quantitative in nature (see, for example, Caban et al., 2005; Munroe, 2001; Watters, Own & Munroe, 2005; Dalby et al., 2009a; 2009b), and although these studies may provide solid information about various characteristics of the DB population, these methods are restricted to providing statistical information. As such, quantitative studies fail to provide an in-depth understanding of the individual experiences of those that are DB and fail to capture the "voice" of those that are DB, information that would be essential for service planning purposes given the diversity among this group. That said, few qualitative studies have been completed with the adult DB population which would aid in planning.

Because of Schneider's (2006) beliefs that "there is little empirical information available about the everyday lives of people who become deafblind and their concerns" (1), she completed interviews that examined the everyday lives of 8 individuals who are DB (25 to 51 years of age). She found that individuals with acquired deafblindness become "interactionally powerless" in a world based on the ability to see and hear in the physical and social environment. To compensate for this powerlessness, her participants reported 4 strategies to reduce this lack of power: (1) managing and maintaining their support relationships; (2) surviving others' perceptions of their DSL; (3) presenting different sides of oneself, depending on the situation, in order to maintain some control of how they are perceived by others; and (4) doing things differently or in other words, interacting with one's surroundings in new ways (e.g., developing strategies for communication, obtaining professional help). One of Schneider's (2006) recommendations was that professionals working with individuals who are DB must assist them in "negotiating a place in a hostile world" by providing them with adequate education and supports and understanding the relationship between their DSL and psycho-emotional issues.

A qualitative study completed by Heine and Browning (2004) among 10 individuals with vision loss (60+ years of age), some of whom had no hearing loss, examined their communication and psychosocial perceptions. The study revealed that communication difficulties occurred frequently and that breakdowns in communication affected the ability for social opportunities. Unfortunately, this study examined older adults who were legally blind and possessed "normal" or self-reported hearing impairment. As such, the population at hand will not necessarily face the same issues as individuals who are DB.

One of the objectives of the study completed by Watters, Owen and Munroe (2005) was to collect information about the successes, barriers and service needs from congenital or acquired DB individuals or their parents/advocates. Interviews and focus groups were conducted across Canada. A total of 44 consumers participated, with 42 having acquired DB. The major themes for the consumers included: (1) how participants felt when they first realized they were DB (e.g., loss of independence, including mobility restriction and difficulties communicating; loneliness/isolation; myriad of feelings from anger, frustration, sense of failure); (2) typical day in the life of someone who is DB (dependent upon level of vision loss and access to intervenors [who communicate with and facilitates the person's interaction with people, places and things by providing information about their environment]; wide range of activities); (3) accessing services in the community (limited by availability of intervenor services; need to rely on friends/family; communication and public transportation difficulties; physical inaccessibility of public buildings; lack of understanding in the general public about deafblindness); and (4) opinions about community service limitations (shortage of trained intervenors and lack of intervention programs; interactions with general public; need for public education).

To date there appears to be a significant dearth of qualitative studies examining the experiences of adults who are DB. If the lived experiences of this population were better understood, in conjunction with information from quantitative studies, providing the necessary and relevant supports and interventions, including intervenor services, would be not be as arduous a task.

As such, the overall purpose of this exploratory research was to examine the lived experiences of individuals with acquired deafblindness. Specifically the challenges individuals with this DSL face, their coping abilities and their future goals were explored through the use of semi-structured face-to-face interviews.

Methodology

Participants

Individuals were recruited from a larger pilot study examining the utility of a standardized assessment, the InterRAI Community Health Assessment (InterRAI CHA) and Deafblind Supplement (Dbs). During the pilot testing of the InterRAI CHA and Dbs, assessors recruited individuals to participate in the interview portion of the study and provided the researchers with the names and contact information for these individuals. In total 7 individuals with acquired DSL were recruited.

Procedure

After agreeing to participate in the interview, each individual was contacted by a member of the research team in order to schedule an interview. A consent form was completed prior to partaking in the face-to-face semi-structured interview, which was digitally recorded and subsequently transcribed verbatim. Three of the 7 subjects required an intervenor/interpreter to assist with the interviews, the remaining 4 subjects did not. The project covered the costs of all intervenor/interpreter services required by the study participants. The role of the intervenor/interpreter was to facilitate communication with the interview by using the form of communication preferred by the participant. Some background information from the standardized assessment was used to "personalize" or guide the interview with each participant (e.g., diagnosis, age, gender).

Determining Sample Size/Power

There are no specific rules for determining sample size in qualitative research. According to Patton (2002), "sample size depends on what you want to know, the purpose of the inquiry, what's at stake, what will be useful, what will have credibility, and what can be done with available time and resources" (p. 244). Once replication of the themes from the participants occurred, the research team concluded that saturation of the data had been reached and no further recruitment of subjects occurred.

Credibility of the Data

Utilizing data triangulation (i.e., using multiple data collection methods: information from the qualitative interviews, information obtained from the assessment, field notes gathered by the interviewer) and investigator triangulation (i.e., multiple researchers for analyses) strengthened the credibility of the data (Lincoln & Guba, 1985; Patton, 2002). Both of the researchers analyzing the data had more than ten years of experience conducting qualitative research.

Data Analysis

Phenomenology, the theoretical orientation used to guide the analysis, explains how "human beings make sense of, experience and transform experience into consciousness, both individually and as shared meaning" (Patton, 2002: p 104). Each participant's experiences were explored through the use of in-depth interviews, after which a critical content analysis was conducted for all sources of data collected. Two researchers analyzed the data independently and then met to discuss emerging themes within the data. This paper will specifically focus on two of the emerging themes derived from this analysis: (1) challenges faced by individuals with DSL; and (2) goals and preparation for the future.

Results

Description of the Participants

In order to protect the privacy and anonymity of the participants within this study, limited background information will be presented in order that the chance of participants being identified is diminished. The participants (n=7) ranged in age from 44 to 88 years of age. All of the participants were considered to be functionally DB and had been assessed by a service provider organization and were receiving government-funded intervenor services or were on a wait list for this service. Five of the participants were male. All subjects had DSL, although the severity of the losses varied between individuals. In total, 3 participants had been diagnosed with Usher Syndrome.

Theme 1: Challenges of DSL

All of the participants discussed the myriad of challenges they faced on a daily basis. The majority of individuals reported experiencing difficulty with the following: (1) difficulties with communication; (2) compromised daily activities; and (3) a lack of spontaneity and independence. Each of these three subthemes will be discussed in turn. It is important to note that all quotes are provided verbatim in order that the essence of every viewpoint is conveyed. Additionally, all seven subjects will be identified as P1 through P7.

Difficulties with Communication

Each of the subjects reported having difficulties communicating with individuals, either one-on-one or in group settings. For example, one individual reported that lighting and distance affected her ability to communicate with individuals if she was unable to see adequately.

Communication with other deaf [individuals] or interpreter is fine, but if too far from me, I can't see it, or [too] dark. I need the help of communication with hands ... feeling. ~P3

This individual went on to say that larger social gatherings posed challenges and that individuals with no sensory impairments sometimes needed to be reminded of the limitations faced by individuals with sensory losses.

... parties, social fellowship presentation. I find quite challenging [for me]. [When a person] tried to talk with me and I can't see [them], it must be close to me, and I also tell them I need a bright light to see better. I know some of them forget about me. They weren't thinking that I can see [them], so I must remind them about me being able to need to see it. ~P3

P5 reiterated this viewpoint with the following quote:

Well, one-to-one, and if someone's close to me I do fine. I can get by. But in a group setting, uh, it's difficult - very difficult

Another individual talked about his struggles communicating with his support group who were primarily deaf, and his inability to use sign language. Even though American Sign Language (ASL) is possible for some individuals who are deaf, this is not necessarily possible for individuals that also face visual impairment. One individual with Usher Syndrome, who faced primarily hearing loss and managed to maintain vision until recent years, commented the following:

I think that in part this would be the place where I feel that I am somewhat in between roles of [the] deafblind culture. So for example, of our total group which is primarily sign, I could never understand sign. I see fingers and things flying [around] and there is absolutely no possible way I could use sign language. ~P6

This inability to communicate with his support group left him feeling like he did not fit in with either the deaf community nor the community with no impairments, but that he did not completely fit in with the deafblind community either.

And I find that I neither fit in the hearing sighted role, nor do I really fit ... [have a place] in the deaf-blind community. ~ P6

Individuals that spoke with accents also posed problems for some participants and limited the participants' abilities to hear and thus communicate with the parties in question. For example, one woman stated that after her cochlear implant she is now able to engage with individuals more, as long as they do not have accents.

I can go out walking and, and with groups that walk and, uh, picnics and stuff like that. With, with people who'd be... have... some, uhh, empathy and don't have accents, so yes I can, I can deal a little more. ~P7

P7 also commented that "we're getting a lot more people in services with accents" and this created difficulty accessing the services required. In fact, services might be refused by the client if they could not understand the intervenor and if communication was highly compromised between the two parties.

The inability to communicate with society, whether with other individuals with sensory impairments or not, was one of the major challenges faced by the participants. Inadequate environmental conditions, the presence of accents, and the lack of ability to utilize sign language were some of the barriers cited as compromising the ability to communicate with the world. Even more troubling was the fact that one participant felt the need to apologize to individuals for her sensory losses.

For the most part I try - I - I ask - I usually identify that I'm hearing impaired, so I prepare people for the - I would usually put in the form of an apology, and people say I shouldn't, I say "I'm sorry I might have to ask you to repeat things". ~P6

Compromised Daily Activities

Each participant discussed how their day-to-day activities were compromised by their DSL. Daily activities that for individuals without sensory losses take for granted often imposed challenges for those with DSL. For example, mobility and/or navigating unfamiliar environments was cited as problematic for many individuals. Although most individuals were relatively comfortable in familiar environments (e.g., their own home), new surroundings were somewhat difficult.

I still don't know, umm, the, the, uhh, like in the house took, took, umm, I'd say, umm, you know even though you're in a house everyday, you're not comfortable with it. I guess about a month you know I'm talking moving everyday, most people think well after a few days you know what you know everything, well you don't. You've, you still have this picture in your mind and when you [move] out of this room, and where are you? And where are going and that kind of thing and then my neighborhood, I still don't know it. And that's gonna take a long a long time partly because the umm mobility instructor isn't available as much, they don't work with you as often umm so if they're working less, you're not covering much ground and you can't, you've you've gotta get to a certain level of confidence before you can start practicing what you've what is being taught. ~P7

Most difficult was navigating unfamiliar environments outside of the home, environments that could not be controlled. The following quotes depict this issue:

I'm at a point right now that a relatively small (uh-uh) qua-qua-quantitative loss can end up - can result in a huge qualitative loss of, you know, function. So going out for a walk, for me is not stress free - It's not a way, you know, you're stressed out so you go for a walk - so going out for a walk is distress. ~P6

My challenge is great because [of my] vision. I can't see [in] the dark. So I use[a] white cane to help me walk through places at night. Also, my deaf friends help me walk through the places at night. They are worried about me. I told them I'm ok, that's all I need is for help to walk together at night. It is a big challenge for me, and also a challenge to use the stairs. I can't see and I ask friends to help me. ~P3

Individuals felt that this inability to navigate the internal and external environments greatly affected their independence and level of activity. The following quotes provide evidence of this:

A lot of activities I did before uh a long time ago I could do on my own (laugh) uh um but no I can't do them now. I um, like running or just walking on my own or um I can't do, I can't do any sightseeing. Um [pause] I do very little compared to what I used to do before. ~P5

I don't consider it, with the hearing that I have, [that I am] unsafe enough to travel independently. So I either have to take a taxi or umm or pay a [taxi] umm and even then pay a [taxi] only takes you to the door and definitely taxi drivers aren't going to bring you in, in the building exactly where you want to go. So you, you have to be able to somehow get to the location within a building and sometimes that's a problem especially if it's a big one. I would [not] be able to just you know travel to and do independently unless there's a volunteer. ~ P7

Mobility-wise ... I basically have no independence. I can't, I can't go off on my own to walk down the street because I don't have {pause} my hearing's not good enough to detect where, where, the traffic is. ~P5

Compromised mobility, whether the result of impaired vision or hearing, was only the tip of the iceberg in terms of affected activities of daily living. Participants also reported having difficulties with issues surrounding the purchasing of food and/or food preparation. Individuals discussed the difficulties associated with locating items within a grocery store and needing help getting to and from the grocery store:

So in, in a grocery store, I might be looking at (uh) just a section of, if you're looking at the Campbell's soups for example, I really don't see a lot of letters, at a distance of reading, on one can of soup, or cereal. Whatever... (um) and transporting back and forth, you know, one of the issues is that when you're using a cane, or a dog, you've also lost one of your hands. That's one of the things that's, you know, difficult ... ~P6

I have help to see the prices of shopping and about ordering food at restaurants. I enjoy [having] someone to help me. ~P3

My cousin takes me grocery shopping for staples once a month. ~P4.

Participants reported difficulties preparing food or handling food.

Preparing meals can be very tough. I do not cook the way I used to cook ~P6

I have to be very careful when I carry anything liquid. ~P5

Other daily activities like reading, house cleaning, and using technology were deemed problematic for many individuals with DSL. The following quotes depict these concerns:

There's this huge loss of activities that I would have been doing {pause} doing ten years ago ... so going from a point where I'd be cleaning and maintaining, you know, to having trouble cleaning myself ...~P6

I know that, umm, a lot of independence is really, really, difficult now a days and I've, I don't, I, I don't know who can address it or what we're going to be able to do about it but now more and more and more things are going with, umm, digital displays. Everything from the oven on the stove is digital...The other day I was, I was, in another store that switched over to, umm, their debit machine now is, umm [pause] ... you have to use a little pen and you know and hit the buttons and that makes it totally inaccessible for me and, that means, I can't go anywhere without an intervenor if I can't even, you know, punch out my number. Before that was easy to do. You used the keys and you knew. ~P7

So it's been very hard to read. I was a very big reader in my life. That's kind of difficult because I'm assembling words because I'm only taking in one or two letters at a time. ~P6

One other area of concern was the inability to be able to monitor one's health appropriately, particularly when there was no partner in the picture.

If you live alone, (uh) there's always going to be things that (uh) a partner, or whatever would notice perhaps. I'd imagine many of the issues, kind of health issues with people in (uh) later life are noticed by their partner [that they are with]. You know there are certain things I can't monitor myself...~P6

Also in the area of health, participants cited aging and age-related changes (e.g., increase in chronic conditions) as factors that further exacerbated the inability to cope with DSL. P4 summarizes his frustrations as follows:

... what I can do, and at age 88 with arthritis, it is even more limiting [because of the hearing and vision loss].

In summary, daily activities posed a challenge for all of the participants with DSL. Many of these activities could only be completed with assistance, often with the help of intervenors or volunteers. P1 reported that unfortunately many of these intervenors or volunteers "didn't always come" for the appointment or "didn't always want to stay" when they did arrive, thus making completion of activities difficult.

No Spontaneity! No Independence! What a Life?

Many participants believed that they were not able to live with spontaneity or independence because of their DSL and their need for support, sometimes continuous support. For some, they felt at times that their DSL limited their ability to have a full life, or the life they wanted to lead. For example P1 stated that "with intervenor help I can do what I want, but independence is better". Another participant conveyed the sentiments poignantly about the inability to lead a life of spontaneity and independence:

Well the challenges, there are, umm, just you, you don't have, umm, you don't have any spontaneous life. You can't just decide when you see something that you'd like to go to. A lot of times I don't get a lot of, umm, a lot of, umm, notice cause people tend to do things on the fly. You get two days notice something's happening. Uh, maybe because I don't hear, hear as well, and I'm not hearing it from the radio. I might hear from emails, but it's delayed and by the time I get it I've only got maybe 2 days to try to go. And I just can't do it because, umm, because there is no way to get there and then get intervention. So, uhh, it's difficult to, to have, uhh, umm, a life where you where you get to do some spontaneous things, everything is, is, uhh, scheduled. Umm, I think if everybody had to live from the schedule they would feel a lot more stressed because it's fun to be spontaneous and it's also healthy if, if you have control. We don't have that control. We don't have the spontaneity. Ha, so that's a problem. Emotionally it's a problem and it's a problem because society has become more like that. ~P7

Other participants talked about the loneliness and isolation they experienced in their lives as a result of their DSL, loneliness that impaired the ability to have a "full life". P2 provided the following comments about this isolation that was either self-imposed OR the result of the DSL:

I read all day, um, and that is, is quite isolating. The street outside is very, very noisy and a very dangerous place to be if you can't hear your way around. And so for the moment until I can find digs, um, I'm, I'm here and that's what I do.

I'm so involved in what I'm doing here, uh, its one thing that I, I, I have, uh, [a] certain degree of, um, self-imposed isolation and I, I am still a relatively newcomer to the city, um, and one of the problems in participating in any kind of activity is the level of noise that, that I have to deal with and an intervenor can be helpful there. But so far I haven't [reached] out ...

It's easier for me to look at how hearing loss has, has contributed [to] my isolation, uh, as opposed to blindness ...

Others grieved for the life they could have had and were frustrated by their difficulty "fitting in" with society as a person with DSL.

It's difficult sometimes for people in the mainstream culture to, uh, integrate with a disabled person ... I - I made some poor career choices perhaps, I was involved in visual art for much of my life, so it's just something now that can't be done. Uh, I miss it very much. ~P6

Individuals with DSL reported leading lives that often lacked spontaneity and independence, resulting from their need for continued support from intervenors or other support people.

Theme 2: The Future~Goals and Preparation

All participants had reservations about their future. Many of the individuals expressed that they were not too optimistic about the future, and for some, the presence of a degenerative disease contributed to this lack of optimism.

And its, um, it's, it's difficult, [for] people with disabilities, or at least people, with people who are blind. Um, and perhaps deafblind are expected that the expectations are very low. [pause] We [are] just people~P2

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I would like to be optimistic, if there was a way that I could be more hopeful with the future. But it's very difficult ... To believe that something is getting better and to be hopeful is almost a form of denial ...because [my DSL] going to get (uh) worse and things aren't going to be any easier, they will become harder. So, there's a difficult part of the, uh, reality of trying to be hopeful and optimistic when that's a much healthier way to live your life. But also realizing that with a degenerative condition, that hoping that your life will become better, and easier is ridiculous. ~P6

I think I'm going to be seeing a doctor a lot in my future. ~P5

I plan to eventually go into a retirement residence that has medical help if needed. ~P4

Individuals expressed the desire to be more independent in the future. For example P1 and P3 provided the following:

I'd like to be more independent. It would be amazing for me to go around [by] myself, if I was able to get some of my sight back.

My challenge in the future is being independent on my own, with my white cane when it comes to [my] vision [being] worse.

Others expressed the desire to have their family "learn to communicate with me better" (P1) and be able to travel again. One participant expressed the desire to educate people about her condition:

My goal is to travel all over the states and the country. And my goal is to teach people about Usher Syndrome and the deafness. ~P3.

The presence of intervenors was the key to this independence, and participants wanted to have more access to intervenors to become more independent.

My thought about myself in the future was successful woman who can [be] independent around home. And other places with intervenors or friends. ~P3

Being independent. My independence has gone down, down the hill, down the drain. I need some variety in my life and, and having intervenors, um, around more would help, would help me have that variety. Ya. I think that intervenors are the key to the whole thing, you know? ~ P5

In terms of preparation for the future, most participants said that they were unprepared.

We'll see what will happen. ~P1

I think it would be very difficult to, uh, I think it would be very difficult to prepare for a future. It would be very difficult indeed. ~ P2

Not very well [prepared] ~ P6

It's hard to plan for what will happen cause you never know the next day or next month. ~P1

I just don't like to think about it. ~P5

One participant reported that he was not fearful of what was to come because of the faith that he possessed.

No, because I also have great faith in God and Jesus Christ. Can't beat that for comfort. ~ P4

In summary, most individuals with DB lacked optimism about their futures primarily because of their degenerative disease and the accompanying negative effects (e.g., lack of independence). Having support, namely in the form of intervenors, was key to increasing their independence in the present and the future.

Discussion

These findings from the narratives of individuals with acquired deafblindness revealed the presence of several challenges experienced by the participants, with three issues being highlighted repeatedly: difficulties with communication, compromised activities of daily living and a life with compromised independence and spontaneity. These issues have been identified in previous quantitative and qualitative literature to some extent among individuals who are DB (acquired or congenital) or those with single sensory loss (see, for example, Brennan et al., 2005; Goransson, 2008; Heine & Browning, 2004; LeJeune, 2010; Schneider, 2006; Smithdass, 1980; Watters et al., 2005). It is important to note that qualitative research work that is rich with information for those that have dual sensory loss (not solely single sensory loss) is lacking. The findings from this research not only substantiates the limited findings within the literature, but also clearly articulates the challenges faced by individuals who are DB, from the perspective of the DB, utilizing a methodologically sound design. Most disconcerting was the finding of the lack of preparedness and lack of optimism these participants felt as a result of their conditions, an issue that will be discussed within the discussion.

Undoubtedly, communicating with others and completing daily tasks challenged the majority, if not all, of the participants within this study. Lack of education and information of the general public, as well as lack of intervenors to complete tasks, further complicated these activities for participants. More troublesome was the fact that individuals expressed their periodic, or in some cases, constant inability to live independently or spontaneously due to their deafblindness, issues that at times affected their engagement with society. Loneliness and isolation were reported as consequences, results that mirrored the work completed by Heine and Browning (2004). Although not discussed in any of the interviews, other mental health issues like depression may be problematic for individuals with DSL, and need to be addressed (see, for example, Capella-McDonnal, 2005; Fellingner, Holzinger & Pollard, 2012). Undoubtedly, supportive environments that reduce the challenges encountered by individuals who are DB and enhance their ability to interact, communicate and become more independent are warranted.

Participants also made known the reservations and lack of optimism they held for the future. Living with a degenerative disease, and not knowing when further declines in function would occur, and the subsequent accommodations that would be needed for these new losses, contributed to this lack of optimism. Individuals commented about the lack of preparedness they had for the future, primarily because they did not know what the future would bring them in terms of their deafblindness and the abilities (or inabilities) they would possess. Research completed by LeJeune (2010) among seniors with varying levels of self-reported vision and hearing loss also conveyed concerns about the future and the fear resulting from these concerns. Individuals working with people who are DB need to address the paucity of preparedness for the future that these individuals may possess.

Limitations and Concluding Remarks

One of the challenges in conducting research with individuals who are DB is that of compromised communication. Given the sensory losses of the participants, communication with or without the use of an intervenor was not as straightforward as with individuals with no sensory losses. Further, although the interviewers were all experienced, they had not previously worked with a DB population. While this is not necessarily a limitation to the findings, it was a challenge faced by the researchers that was worth noting. Every step was made to ensure the interview was conducted in a comfortable environment and in a place that was most appropriate for the needs of the participants.

One limitation to the study was that individuals with acquired deafblindness were only represented within this analysis. The main reason for doing so was to increase the homogeneity of the sample and in no way was meant to undermine the experiences of those that are congenitally DB.

These findings, revealed from the point of view of the participants, are invaluable as they portray the daily realities of individuals living with deafblindness. It is important to note that these experiences are not meant to be generalizable to other individuals faced with similar situations; however it is anticipated that these findings can be used as a source of support for this population and for the people who work with them. Further, these findings serve as information and education to those in positions with the ability to exert change on the services provided for individuals with DB. Smithidas (1980) encapsulates being DB poignantly with the following "Blindness takes an individual away from things, and deafness takes him away from people" (1015). So where does this leave those with dual sensory loss?

Research that examines the lived experiences of individuals that are DB assists in providing them a voice --- a voice that clearly articulates their needs for the present and the future. Understanding these needs is vital to the well-being and functioning of these individuals and should not be silenced. It is clear from this research that access to interveners is vital for these individuals across all aspects of their lives. Even though these participants had access to interveners, an increase in the availability of these services would be beneficial to their quality of life and independence. Further research is warranted in this area to help decision-makers and service providers address the needs of the DB community.

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Contributors

Paula C. Fletcher, PhD
Department of Kinesiology and Physical Education Wilfrid Laurier University Waterloo,
Ontario

Dawn M. Guthrie, PhD
Department of Kinesiology and Physical Education Wilfrid Laurier University Waterloo,
Ontario

Email: pfletcher@wlu.ca