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A thematic analysis of a photo elicitation investigating ‘what does it mean to a person to be deaf or hard of hearing?’

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Abstract

Research investigating the experiences of the deaf and hard of hearing population has often found that people have negative experiences, such as social isolation, communication and employment barriers, and barriers to accessing health care due to their deafness. The current study aimed to investigate individual experiences and perceptions of what it means to be deaf or hard of hearing. The rationale focuses on using inclusive methods and raising awareness of these individual experiences/perceptions, so to hopefully improve the treatment of deaf and hard of hearing people within society and in turn, improve their experiences. Photo elicitation was the chosen research method, with participants (n=2) taking part in an online survey.

Three master themes were found, with some emergent themes (1. Aids don't always aid, 1a. Amplifying the 'wrong' sounds, 1b. A visible reminder, 1c. Isolation, 2. It's not all negative, 3. Relationships, 3a. Workplace relationships, 3b. Familial relationships). The themes that emerged from the current study have some relevance in reference to existing literature, and it can be concluded that although not all aspects of deafness appear to be negative, some aspects of society could better accommodate the deaf and hard of hearing population.

Inclusive research like the current study could be replicated on a larger scale, with more participants and a broader range of hearing abilities being involved. Conducting inclusive research such as the current study will allow more members of the deaf and hard of hearing population to share their experiences, and ensure them of the value of their input.

Additionally, institutions such as healthcare and education could aim to educate more thoroughly on deafness and its implications, as well as teaching strategies which may reduce communication barriers between the deaf and hearing communities.

Key words: deaf, Deaf, hard of hearing, experiences, photo elicitation, interview, online survey

To understand the experiences of deaf and hard of hearing individuals, we should first look at the difference between the two conditions. In this context, speaking medically, the term deaf refers to the audiological condition of not hearing, and hard of hearing refers to an individual with mild-to-moderate hearing loss (Berke, 2018; National Association of the Deaf, 2018; Padden & Humphries, 2006; Signhealth, 2018). An individual who has hearing loss of 15-70 decibels will be classified medically as hard of hearing, or with slight/mild/moderate/moderately severe hearing loss (Institute for Quality and Efficiency in Health Care, 2006). However, an individual with hearing loss of more than 70 decibels is classified as deaf, or with severe or profound hearing loss (Squires, Colombo & McKinney, 2019). This medical definition of deafness is the one most commonly used in the hearing community (Adams & Rohring, 2004). Research also suggests that the deaf and hard of hearing population would prefer to be called “deaf” or “hard of hearing” rather than other terms; for example, ‘hearing impaired’ (Creighton, 2004). Considering these findings, the current research will focus on the use of these definitions.

Deafness can also be defined in terms of an individual’s membership in the British Deaf Association (BDA; British Deaf Association, 2015). Some individuals may identify themselves as Deaf (upper case D), as they see themselves as being part of a Deaf community. Those in this community tend to share a language (British Sign Language – BSL, or American Sign Language – ASL) and differ from deaf individuals as they see their deafness as more than a medical condition (Berke, 2018; Padden & Humphries, 1988). Members of the Deaf culture may also celebrate important events in Deaf history, dress in dark colours to improve visibility of hands and therefore make signing easier to read, or go to separate social institutions/schools (Moore & Levitan, 2003). Supporters of this definition emphasise that Deafness is more than a physical complication and suggests that aspects of the personality of a Deaf person (e.g. their social status, intelligence and education) can be overlooked when using a medical definition (Padden & Humphries, 1988). Research has found that levels of self-esteem are likely to be higher in individuals who identify as part of the Deaf community (Jambor & Elliott, 2005).

Humphries (1975; as cited in Berke, 2018) defines the term audism as “the notion that one is superior based on one’s ability to hear or behave in the manner of one who hears” (p.240). The term is rarely mentioned in scholarly articles (Eckert & Rowley, 2013), despite

audism regularly occurring within society (Ballenger, 2013; Eckert & Rowley, 2013). An example of this comes from Action for Hearing Loss (2018) who found in their survey that 55% of participants felt they were treated unfairly at work because of their deafness. Creighton (2004) highlights the profound impact that labelling can have on an individual. The research explains that terms such as ‘Deaf-Mute’, ‘Deaf and Dumb’ and ‘Hearing-Impaired’ are “outdated and offensive” (p.2) and suggests that society should have more respect for the deaf community by not using these terms. This research highlights the importance of: a) not labelling members of the deaf and hard of hearing population as anything that may be potentially offensive; and, b) allowing members of this population the opportunity to identify themselves in terms of their deafness, as they may refer to a medical or cultural definition, or both. Considering all of this, the current research uses the terms deaf and hard of hearing throughout the recruitment process and investigation. However, participants were also given the opportunity to identify themselves in terms of their deafness.

Around 11 million people in the UK have hearing loss, which may range from being hard of hearing, to profoundly deaf. (Action on Hearing Loss, n.d.; Hearing Link, 2018; UK Deaf Sport, 2018). This means that around 1 in 6 individuals face this, making it the second most common disability in the UK (Hearing Link, 2018). As well as this, according to Harris and Bamford (2001), the experiences of deaf and hard of hearing people are widely different to those of the hearing population, and significant barriers prevent deaf and hard of hearing individuals fully participating in performing in social roles such as citizenship, employment, parenting and being a patient. According to research “the shared oppression of people with various types of hearing loss is largely unknown and uncontested by those who have hearing ability” (Ballenger, 2013. pp.122), and the current research aims to address this.

Gloucestershire Deaf Association (2017) found that 73% of deaf and hard of hearing people said they feel lonely because of their deafness. Similarly, Action on Hearing Loss (2018) conducted a survey which involved 1072 individuals who were deaf or hard of hearing and found that 65% of participants reported feeling isolated at work because of their deafness. Research suggests that the experiences of members of the deaf population have similarities to that of members of other hearing minority groups (Paranis, 1998), and that they are likely to face significant communication barriers in their everyday life (Barnett, 2002; Foster, 2012; Scheier, 2009).

Many dimensions of an individual's life can be affected due to their deafness, such as their psychological and social functioning. (Martin & Bat-Chava, 2003). An individual with deafness may also face barriers to accessing healthcare. Ubido and Huntington (2002) found that deaf participants "face a lack of awareness by health staff of how to communicate with them" (p. 247), therefore affecting their ability to, and experience of, accessing health care. Daisy (2008) suggests that a positive change can be made if researchers provide members of the deaf population with a safe, trusting environment to discuss their experiences, and a rationale of the current study is to achieve this.

Saunders (2016) interestingly notes that social media has contributed to an increase in social awareness of many causes/communities, including the deaf community. However, the research found that, regarding the deaf community, the increase in awareness and cultural understanding "faces greater friction and less progress in comparison to other causes and communities such as feminism, the LGBT community and people of colour" (p.1). The research does point out that this may be due to most information available online regarding increasing awareness and cultural understanding of deaf and hard of hearing individuals being in American Sign Language (ASL). Therefore, as this information is only accessible to those who are fluent in ASL, this may explain why this culture is facing 'greater friction and less progress' than others.

According to Action on Hearing Loss (n.d.), 60% of individuals who would benefit from hearing aids do not have them. This source also notes that people wait an average of 10 years before seeking medical advice about their hearing, and when they do, GPs have been found to fail to refer between 30-45% of patients to audiology services. Scheier (2009) explains that deaf individuals face higher rates of misdiagnosis of serious illness than their hearing peers.

Aims and rationale

The findings of previous literature provide the rationale for this study - to raise awareness of the experiences of members of the deaf population. By increasing research coverage in this area, it is hopeful that more individuals with hearing loss would be encouraged to seek medical advice, but also encourage organisations provide more training to GPs to avoid patients going without appropriate treatment and support.

Firstly, the researcher will ask participants to answer the question “What does it mean to you to be deaf or hard of hearing?” Participants will take 5-10 photos that reflect their answer(s) to this question. Previous research has suggested that more should be done to investigate individual experiences of members of the deaf population (Munoz-Baell & Ruiz, 2000). The use of photo elicitation addresses this as individual experiences can be better explored by asking participants to take their own photos, as oppose to forming a structured interview which requires researcher-led direction (Bates, McCann, Kaye & Taylor, 2017). Previous research (e.g., see Hughes, Burton & Dempsey, 2019; Jespersen et al., 2019) have used photo elicitation when investigating the experiences of living with various disabilities. However, no prominent research appears to have investigated the experiences of deafness specifically using this research method. The current research hopes to show the value of using this method when investigating the experiences of this population.

Although the claim by Munoz-Baell and Ruiz (2000) may be considered out of date, no prevalent research has been conducted which aims to address this gap in the literature where experiences of deaf and hard of hearing individuals are not being accessed. Based on this, the aims of the current study are to: a) address this gap in the literature, by using participant led methods which will access individual experiences, as well as avoiding disempowering participants by asking potentially leading questions; and, b) increase awareness of the experiences had by members of the deaf and hard of hearing population, which research suggests have often been overlooked or ignored by the hearing population (Ballenger, 2013; Saunders, 2016). Considering that the participant sample is a minority group who have been found to face barriers in their communication, the current study aims to be as inclusive as possible by offering a choice of method, so to empower participants and encourage participants of a wider range of deafness to take part in the research.

Method

The current research uses several methods of data collection. In this section, the methods used are briefly summarised. A more detailed explanation of how and why the methods were used can be seen in the discussion section of this report. The current study used photo elicitation, which helped to facilitate the online surveys that followed. The data was then analysed using a thematic analysis (Braun & Clarke, 2006). Considering research by Do

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It (2017) which explains that many members of the deaf population prefer the terms “deaf” and “hard of hearing” to “hearing impaired”, as the terms are more positive, and do not imply a deficit, the current research focused on avoiding being audist (Humphries, 1975) by avoiding the use of potentially offensive terms, such as those mentioned above. Participants were referred to as “Deaf or hard of hearing” and were given the opportunity to identify themselves regarding their deafness as part of the online survey.

The researcher comes from a critical realist perspective, focusing on reality as a continuously renegotiated, debated and interpreted concept. Having this pragmatic perspective meant that the researcher chose the method, in this case a photo elicitation followed by an interview or a personalised online survey, that would be best suited to investigating the research question. Using this method allowed participants to lead the discussion about their individual experiences and perceptions.

Research Design

Sampling participants – inclusion and exclusion. Participants were recruited through word of mouth and the research was advertised on social media. After expressing an interest in taking part in the research, four potential participants were given an information sheet, a consent form and the opportunity to ask any questions. Following this, two participants went ahead with participation. The others did not give reasons for not participating, but merely did not respond.

A homogeneous group was necessary to investigate the research title. The specific criteria for taking part was that all participants must have some level of deafness. Participants were asked how they identify in terms of their deafness; one of the participants identified as having “moderate hearing loss” and the other as “hearing impaired”.

Data Collection Method.

Photo elicitation. Photo elicitation is a research method whereby the researcher uses photographs as an aid in their research. (Bates et al., 2017; Harper, 2002; Meo, 2010). Participants of the current study were asked the question “What does it mean to you to be deaf or hard of hearing?”. They were asked to take 5-10 photos that reflect their answer to

this question and told that they would be given the opportunity to discuss their choice of photos in either an interview or an online survey.

No prominent research has used photo elicitation to investigate the experience of the deaf population, encouraging the researcher to do so and show the value of using participant-driven methods, particularly when looking at groups that may have experienced some injustice and discrimination.

Interview/Online survey. Photo elicitation is usually used to aid an interview (Bates et al., 2017; Meo, 2010). However, the researcher of the current study considered the research focus and the sample of participants when contemplating which research method to use and made the decision to give participants a choice of method to follow the photo elicitation. Participants were able to choose whether they would discuss their photos in a face-to-face interview or on an online survey, which would be personalised to each participant. Interviews are one of the most common methods used when conducting qualitative research (Gill, Stewart, Treasure & Chadwick, 2008) because researchers can obtain a deeper understanding of a particular phenomenon this way than by using more quantitative methods (e.g. questionnaire; Gill et al., 2008; King, 2004; Willig, 2013). However, Gloucestershire Deaf Association (2017) found that 89% of deaf and hard of hearing people said they feel embarrassed to admit they did not hear conversations. It is due to consideration of this finding that participants were offered an alternative method (the online survey) that would not involve any speaking and listening. In the end, all participants chose to take part in an online survey rather than an interview. It is important to consider here however that, although the choice of method may be in support of the Gloucestershire Deaf Association (2017) finding, it may merely be a choice made based on convenience (i.e. it may have been more convenient for the participant to complete an online survey in their own time, than organise a meeting time with the researcher for a face-to-face interview).

Constructing and conducting the online survey. None of the participants chose the interview option. Participants were asked to take 5-10 photos that reflect what it means to them to be deaf or hard of hearing. Participants then sent the photos via email to the researcher, before the researcher created a personalised online survey for the respective participant to complete. This involved all information given to participants on the online

survey to remain standardised and identical to the pilot survey, but questions to be more personalised to the participant. For example, one question was ‘Please describe your second photo which appears to be of a stage in a theatre and how it reflects what it means to you to be deaf or hard of hearing’.

Analysis

Method of analysis. The method of analysis used in this study was thematic analysis. This method of analysis of qualitative data recognises and organises “patterns in content and meaning in qualitative data” (Willig, 2013, p.57) and is widely used to analyse qualitative data within the field of psychology (Braun & Clarke, 2006; Fugard & Potts, 2015). Braun and Clarke (2006) explain that thematic analysis allows a piece of research to reflect reality. The current research used inductive approach, meaning that the themes that were identified were the result of the data itself, and not driven by the researchers “theoretical interest in the area or topic” (Braun & Clarke, 2006; p.83).

The researcher chose to analyse the data on a semantic level. As the sample is a minority group who may have already experienced some discrimination, and lacked opportunity to share their experiences, it was important to the researcher that their data not be attempted to be interpreted, as this may lead to the misunderstanding, affecting the validity of the data and potentially leaving the participant feeling disempowered. As well as this, as the method of data collection was an online survey, it would be difficult to interpret the data. Therefore, to maintain reliable and valid data, avoiding this deep interpretation was the best option. This supports Riessman, (1993) who rejected the idea of an investigator independently interpreting participants opinions, as doing so can affect the accuracy and validity of the data collected. Thematic analysis in the case of the current study aimed to find themes within the data, and did not attempt to interpret the participants answers, but took them at face value (Braun & Clarke, 2006).

Ethics

The British Psychological Society (BPS) ethical guidelines were referred to throughout both the planning and the execution of the research (BPS, 2014; BPS, 2018). This ensured that standards were consistently maintained. The BPS (2018) suggests that there are four ethical principles that ought to be considered when a psychologist conducts research:

respect, competence, responsibility and integrity. These guidelines were followed throughout the current study.

The researcher respected participants by ensuring their data was kept confidential (in accordance with the Data Protection Act, 2018), that they were able to give informed consent, and ensured that they had the opportunity to ask any questions throughout the research process. Also, regarding respect for the participants, the researcher aimed to reduce any issues of power affecting the participant's data by allowing the participant to fully control the direction of conversation. Aspects such as compassion, empathy and distress were also considered here, as the researcher ensured the participant had the opportunity to identify themselves in terms of their deafness and did not label them in a way which may have been offensive and/or distressing.

The researcher considered their own competence and abilities and ensured that participants received a debrief sheet which thanked them for their participation and provided them with relevant contact details which may be helpful if they feel any distress or discomfort following their participation. By doing so, the researcher understood that this was a limit of their competence but understood their responsibility to signpost a relevant professional to protect the welfare of the participants.

Finally, integrity refers to the psychologist being honest, accurate and consistent throughout the research process – in the current study participants were able to lead the discussions. Participants chose their own photographs that described their perception of what it means to be deaf or hard of hearing and discussed those, ensuring the data was not affected by the researcher's own interests or potentially biased representations. (BPS, 2018).

Results and Analysis

In this section of the report, the master and emergent themes that emerged from the data are highlighted and discussed. A 'theme' can be defined in many ways (Willig, 2013), however most definitions will recognise that a theme involves the presence of a pattern (Braun & Clarke, 2006; Joffe, 2012; Willig, 2013).

Analytical Overview

The three master themes are listed, along with the emergent themes.

1. Aids don't always aid

1a. Amplifying the 'wrong' sounds, 1b. A visible reminder, and 1c. Isolation

2. It's not all negative

3. Relationships

3a. Workplace relationships and 3b. Familial relationships

Below is a thematic analysis of the data collected. Extracts from participants online surveys are used as evidence for master and emergent themes and are linked to relevant literature where appropriate.

Master theme 1: Aids don't always aid. In this master theme, we can see that both participants mention experiences whereby their hearing aids, which are devices used to amplify sound waves to help deaf or hard of hearing people hear more successfully (Marriam-Webster, 2019), did not actually aid them (*"my aids often get overwhelmed... meaning that I can't hear people around me very well"*, Participant 1:32-35). Three emergent themes were found within this master theme: amplifying the 'wrong' sounds, a visible reminder, and isolation, and they will each be explained below.

Emergent theme 1a: Amplifying the 'wrong' sounds. This emergent theme explores the recurring expression from participants of the current study that hearing aids often fail to amplify the sounds the individual wishes to hear (e.g., other voices) and instead amplifies unwanted sounds, such as wind, footsteps or music, affecting their experience of being deaf or hard of hearing. Participant one said, "My aids often get overwhelmed with the sounds of wind, traffic and footsteps, meaning that I can't hear people around me very well".

This extract is participant one discussing a photo of them on a walk with their daughter in the park. Research supports this finding, with Moeller, Hoover, Peterson and Stelmachowicz (2008) finding that although in most settings, their deaf and hard of hearing participants used amplification of hearing aids, certain settings such as being outdoors or in a car made maintaining use of the device more challenging. This research was conducted with young people, and it was found that the consistency of amplification improved with age.

However, the finding that particular situations can make use of a hearing aid more challenging is still an important, relevant point to consider. In their online survey, participant two said “Sometimes I have to put the volume up and then down dependant on what is on, Music I have to turn right down as it is too loud and my aids amplify the noise, classical music particularly can be difficult”. Another extract is as follows: “He has such a deep voice that I can’t hear him without the aids and even with the hearing aids I pick up on indistinct murmuring rather than clear enunciated words”.

It has been suggested that users of hearing aids who report problems often require fine-tuning of their hearing aids because of too much amplification of particular sounds, and not enough of others (Dillon, 2008; Nabelek, Tucker & Letowski, 1991). However, as research suggests that individuals experiencing issues with their hearing abilities are hesitant to seek medical advice, taking an average of ten years to do so (Action on Hearing Loss, n.d.), it is not unreasonable to assume that once seeking medical advice, the individuals may again be hesitant to return to a professional if they are experiencing any issues with their hearing aids. The Action on Hearing Loss has no date, meaning that we cannot accurately presume that this finding is representative of deaf and hard of hearing individuals today. Hopefully, today’s hard of hearing individuals feel comfortable seeking medical advice due to the availability of successful hearing aids increasing over time (NHS, 2017).

Dillon (2008) explains that providing individuals with patient-centred, individual methods of tackling their issues will be more appreciated and make methods more easily learnt by patients. Providing education to the patients regarding the individual differences that can be experienced may “increase the likelihood that hearing aids will be fully used and that residual communication difficulties will be minimized” (p.15). As well as this, some advice suggested by research is that patients should be educated on cognitive based listening exercises which will aid their hearing abilities regardless of their hearing aids (Dillon, 2008; Song, Skoe, Banai & Kraus, 2012). This may involve the listener looking at the talker, as well as their surroundings, and involving their family in this education to improve their awareness and encourage them to talk directly to the deaf/hard of hearing listener, as opposed to talking with their back to them, for example.

In the case of participant two, this advice and education may be particularly helpful. Particularly by educating family members on how to improve their hearing ability – her

husband who she discusses having trouble hearing due to his deep voice which sounds like a merely a murmur to her sometimes, could be educated on ways to enunciate his words to improve their communication. In the future, deaf associations could advise their deaf and hard of hearing patients and their families to work on enunciating their words to improve communication. However, although this may be helpful advice and has been found to be beneficial, in some cases it may not be. For example, in the case of participant one who explains the difficulties with their aids when out on a walk with their daughter, it will be difficult for them to apply these strategies due to the child being too young to be educated, and the unavoidable loud noises such as traffic and wind that occur when one is outside.

Emergent theme 1b: A visible reminder. This emergent theme discusses participants recognition of their hearing aids as a visible reminder of their deafness. Participant two said in their survey “It is a visible reminder that I have a hearing loss” when discussing their photo of a hearing aid. As well as this, participant one’s quote is as follows:

“This is a photo of me holding my daughter seconds after giving birth. I think this reflects my deafness because my hearing aids are in clear view. Even I’m [sic] my most natural and bare state, my hearing aids are still part of me”.

Although hearing aids provide obvious benefits to the user (Mulow, Tuley & Aguilar, 1992; NHS, 2017), the data implies that there is more to wearing a hearing aid than having their hearing abilities improved. Participant one explains that her hearing aids are still part of her, even in her most “natural and bare state”, talking about moments after giving birth to her daughter. This acknowledgement suggests that using a hearing aid provides not only improvement to hearing but is also a big part of what it means to be deaf/hard of hearing due to its physical appearance.

NHS (2017) explain that hearing aids have improved over time and are now smaller and neater than they used to be. The constant evolution of technologies such as hearing aids provides hope that hearing aids will continue to work more effectively and efficiently, and it is possible that in the future, their purpose will solely be to amplify sound and improve hearing, and the physical appearance of the aids will be minimized further or completely.

Emergent theme 1c: Isolation. In this emergent theme, data from both participants describes their experiences of isolation because of their being deaf/hard of hearing.

“...this is my working environment and as you can see from the picture we sit with our backs to each other. I find this difficult as I need to be facing a person to hear them correctly despite having two aids”

This extract shows participant two discussing feelings of isolation within their workplace. Research has found that 65% of deaf and hard of hearing participants reported feelings of isolation at work as a result of their deafness (Action on Hearing Loss, 2018). Participant one also discussed a similar experience: “For many people going for a walk can be a social experience but with my hearing impairment going outside with others can be difficult”.

Research highlights the isolation experienced by deaf and hard of hearing individuals; Bloom, Maschark, Veveloed and Knoors (2014) found that these individuals generally have fewer friends than hearing peers, and the friendships that they do have are of a lower quality. Furthermore, Luey et al. (1995) points out that being an individual with deafness or who is hard of hearing can be an isolating experience due to the difficulties communicating with others. The research suggests that making connections with other individuals or groups with the same condition can encourage “companionship, support and a sense of shared mission” (p.181) which may reduce these feelings of isolation and loneliness.

The isolation experienced by members of the deaf and hard of hearing population can be compared to those of other minority groups (Paranis, 1998). This is supported by Gregory and Hartley (1990), who suggest that deaf people show all the characteristics of a minority group, for example, deaf individuals tend to marry others who are deaf, are given a lower status due to their barriers using a spoken language and are unlikely to acquire high status positions in society. However, the book that this reference comes from could be considered out of date, as it is 29 years old, and it is possible that, due to this, it may not be accurate. For example, over the past almost three decades, it is possible, and hopeful, that an individual who is deaf or hard of hearing will find it easier to acquire high status positions in society than they did in 1990.

Davis (2007) explains that the perceptions of deafness has evolved over the three decades prior, with deaf individuals now being viewed not only “as hearing-impaired, but as a linguistic minority, isolated from the dominant culture because that culture didn’t recognise or use ASL” (p.2). ASL (American Sign Language) is the American equivalent of British Sign Language (BSL), so although the current study is set in a different culture, the findings are still comparable. In order to tackle this issue, it would be practical to suggest that institutions such as the education system should incorporate sign language into the material they deliver. This would not only reduce communication barriers between the hearing population and those who use sign language as their main means of communication, but also give hard of hearing participants an alternative means of communication so that the potential barriers discussed here would be minimized or removed.

Master theme 2: It’s not all negative. In this master theme, data is collated that reflects both participants expressing that not all their experiences of deafness are negative ones. This master theme stood alone, with no emergent theme(s), and extracts below show participants expressing some, what could be classified as ‘perks’ of being deaf or hard of hearing. Firstly, participant one said, “It’s not always bad though, my impairment means I get front row seats whenever I go to see a show, which I’m very thankful for”. Similarly, participant two expressed that their deafness does not always appear as a hinderance. “My kindle is wonderful and I can disappear in to a world of books and even take my aids out of my ears so I can truly relax”.

Both participants here express that there are some positive aspects that they have found associated with their deafness. There appears to be a gap in the research considering this finding, as research into the experiences and perceptions of deafness has predominantly a negative focus (i.e. those discussed throughout this report – isolation and frustration for example). The lack of supporting research of this theme makes the finding particularly interesting, as it must be considered that previous research in the area has avoided investigating positive experiences, whether than be intentionally or unintentionally.

The fact that the current research allowed participants to lead the discussion by having them choose their own photos that reflect what it means to them to be deaf or hard of hearing and describe their photos after this, may explain this unexpected finding. Previous research

into the area may have used methods such as interviews or questionnaires, which meant that the discussions are likely to have been researcher led (Bates et al., 2017). Future research should use inductive methods, such as those used in the current study, to ensure participants are able to fully express their individual experiences and perceptions, as oppose to answering questions that may be potentially leading and driven by pre-existing theory and literature.

Master theme 3: Relationships. In this master theme, we will discuss some of the implications of the participants being hard of hearing on their relationships with others. Deafness does not only affect the deaf or hard of hearing individual, but also those around them due to how much it interferes with communication (Luey, Glass & Elliott, 1995). Within this master theme, two emergent these were found: workplace relationships and familial relationships.

Emergent theme 3a: Workplace relationships. Participants express feeling concern for colleagues regarding their deafness. This involves feelings of frustration and embarrassment when doing everyday tasks at work that are made difficult because of their being hard of hearing. A quote from participant two:

“I find it frustrating and embarrassing when I have to consistently ask my colleagues to repeat what they say when they face me. I miss out on information too, but the room is set up in this way and can’t be changed”.

Some research has been conducted which investigates practices in place in workplaces that accommodate issues experienced by hard of hearing employees. Harris and Bamford (2001) found that some employers are supportive of their deaf/hard of hearing employees, and are happy to accommodate to their needs, but some saw their extra needs of provision as the problem. Scherich (1996) found that “situations considered the most difficult for persons who are deaf or hard of hearing are group or multi-speaker situations” (p.27). This is relevant to participant two, as their photo shows an office of multiple people, who all face different ways, and they describe feeling frustrated and embarrassed having to ask her colleagues to repeat what they are saying. This difficulty hearing may be due to the way the office is set up, as participant two suggests, but the multi-speaker environment may also contribute, as voices will overlap, and the hearing aids may struggle to differentiate between

the voices. Due to these feelings of frustration and embarrassment, along with the barriers of communication themselves, deaf and hard of hearing individuals may struggle to maintain healthy relationships with their co-workers. Action on Hearing Loss (2018) supports this suggestion, finding that 65% of 1072 hard of hearing or deaf participants reported feeling isolated at work because of their deafness.

Harris and Bamford (2001) found a lack of flexibility in the service provision for hard of hearing and deaf employees and suggested that the provision that could be seen was service led, as opposed to needs-led. This suggests that further understanding of the individual experiences and needs of deaf and hard of hearing people in the workplace is needed, and action should be put in place in consideration of this. This may, in turn, improve the communication and relationships between the deaf/hard of hearing individual, and their hearing colleagues.

Emergent theme 3b: Familial relationships. Within this emergent theme, both participants express having concern for their familial relationships because of their own deafness. As shown below, participant two expresses feelings of concern regarding a spouse who has trouble communicating with them,

“I struggle to hear him and have to ask them to repeat what they have said which is frustrating for them too”,

“I have the TV on fairly loud and without my aids it is about 2/3 volume which can be hard on anyone else sitting with me”,

“This is my husband and I really cannot hear him when he has his back to me, I can’t tell you how often this has caused problems as he has thought I have been ignoring him”.

Hallberg (1996) found that in marriages where one half is deaf or hard of hearing, the condition often caused misunderstandings and irritations within the family, and this in turn had a negative effect on the relationship of the couple. This is supported by more recent research, which found that communication barriers occurring as a result of the deaf/hard of hearing individual (such as repeating oneself, maintaining face-to-face contact, raising one’s voice) had led to the development of negative feelings with the marriage. Sixty-nine percent

of participants in this study reported feeling frustrated because of these difficulties (Govender, Maistry, Soomar & Paken, 2013). As mentioned in the analysis of the emergent theme 1a, education on ways to improve communication may be beneficial here. Participant two's husband was photographed with his back to her, however, he may be more inclined to face her during conversation if thoroughly educated and advised by deaf associations on the benefits of doing so.

Participant one expressed similar concerns, but regarding a young child who is dependent on them. In their survey, they said "I had to chose [sic] a monitor which had higher than average volume capacity and noise-light display...This used to make me nervous that I wouldn't hear my baby crying at night but I have adapted to it well".

Parental anxiety can present itself at any time during pregnancy or after the birth of a child, and can present itself as low mood, sadness, panic, worry and anger (Hoggard, 2017). Hoggard (2017) suggests that pre-existing anxiety can also contribute to the development of parental anxiety. As well as this, research has suggested that being deaf or hard of hearing can contribute to mental health conditions, including anxiety. (Carmen & Shelley, 2002; Kvam, Loeb & Tambs, 2006). These findings suggest that individuals who are deaf and hard of hearing and have children are at high risk of developing parental anxiety. We can see by participant one's extract that they may be experiencing parental anxiety, having the worry that they would not hear their baby crying. Their worry was so extensive that they chose a baby monitor with noise light display, and a louder than average volume. This finding suggests that support systems could be put in place to improve the anxiety that may be caused by not only becoming a parent but becoming a parent who is deaf or hard of hearing, which in turn may improve the relationship that can be built between the hard of hearing parent and their child.

Calderon and Greenberg (1997) provide recommended practices for hearing parents with deaf children. Singleton and Tittle (2000) proposes that these recommendations can be applied to deaf parents with hearing children with minor adaption. These recommendations include: working with the entire family system to improve communication, the development of a solid communication base and encouraging parents seeking social support so to improve their confidence in their parenting. These recommendations may be beneficial to participant one, as it will improve their confidence, and therefore hopefully reduce their anxiety, whilst

also providing helpful communication strategies which will provide a healthy, strong relationship between themselves and their child.

Discussion

Overall, the results of the current study showed three master themes. Firstly, 'aids don't always aid', with the emergent themes: 'amplifying the wrong sounds', 'a visible reminder' and 'isolation', which highlighted some of the issues that the participants experienced with their hearing aids – a device which intends to improve the wellbeing of the individuals. Secondly, 'it's not all negative' interestingly was not in line with previous literature in this field. The participants both explained instances where their deafness had 'perks', which they may have brought up due to having the freedom to lead the discussion on their individual experience, rather than being part of a researcher led study. And finally, 'relationships', which the emergent themes: 'workplace relationships' and 'familial relationships', which highlighted how the participant's deafness affects their relationships with those both at work, as well as within the family.

In terms of the level of analysis conducted, themes were identified on a semantic level as opposed to a latent level, as answers did not have to be interpreted by the researcher, reducing the risk of potential misinterpretation and disempowerment. Additionally, as inclusivity was crucial in the current study, the choice of method reflected this. It was hopeful that allowing participants decide which method they would prefer (interview or online survey) would ensure; a) individuals who express themselves better vocally would have the opportunity to do so in an interview and, b) individuals who may feel negative feelings when in situations where they have trouble hearing the opportunity to do an online survey. Indeed, Gloucester Deaf Society (2017) suggest 89% of deaf and hard of hearing individuals express feeling embarrassed in these latter situations

The current study has highlighted the value of using photo elicitation and a participant-driven, inclusive research method when investigating the experiences of deaf and hard of hearing individuals. In terms of how the current study may influence future research, researchers could also focus on the importance of inclusivity. Future studies allow data to be collected with the aid of interpreters. This would allow profoundly deaf participants an even wider range of possibility of data collection. This potentially could attract the attention of a

wider range of the deaf/hard of hearing population and help to empower them to discuss their experiences freely.

Although the current study did not involve any individuals who identify as profoundly deaf, and/or uses Sign Language as their main means of communication, future research could aim to access this population. It would be valuable to investigate whether experiences and perceptions of what it means to be deaf or hard of hearing are similar across all cases or differ according to the extent of the participant's hearing abilities.

Reflexivity

Reflexivity is a crucial process when conducting qualitative research (Berger, 2013; Dowling, 2006; Langdridge, 2007; Shaw, 2010) particularly when working with underrepresented populations, such as those involved in the current study, as there are potential dangers in misrepresenting the participants (Langdridge, 2007). The reflexivity process, according to Langdridge (2007) involves researchers being "conscious of and reflective about the ways in which their questions, methods and very own subject position might impact on the psychological knowledge produced in a research study" (pp.58-59). The researcher of the current study was reflective throughout the planning and execution of the research, considering the several questions suggested by Langdridge (2007).

The researcher acknowledged that, due to not being part of the deaf and hard of hearing population themselves, that they do not have a close relationship to the topic; however, the researcher has a close friendship with someone who does identify as hard of hearing. Although this relationship may have sparked the interest of the researcher, influencing their decision to conduct the following research, it did not influence findings/conclusions. The researcher also considered how their subject position may have influenced the analysis, as suggested by Langdridge (2007). Photo elicitation was intentionally chosen as the research method as it would allow participants to lead the discussions of their experiences, and therefore ensuring that the researcher did not influence the validity of the data.

Future Applications

Potential application for wider society could include training from health care professionals on strategies for better communication. This could be delivered to both the deaf/hard of hearing individual, as well as their close friends and family. We can see that this application would be helpful looking at the findings of the current study, where both participants expressed barriers to communication with their close friends and family as a result of a) their hearing aids amplifying the “wrong” sounds, and failing to amplify voices, and b) their family members and work colleagues trying to converse whilst having their back to the deaf/hard of hearing individual. If healthcare professionals educated the deaf individual, as well as their friends and family on how to effectively communicate with one another, these barriers may be reduced.

As well as this, more should be done to train employees working within healthcare sectors on ways to improve the accessibility of health care services and the deaf and hard of hearing individual’s understanding of issues regarding health and well-being. Research suggests that despite policies that are in place to promote equality, there is “little leverage for improving services and therefore facilitating the inclusion of deaf and hard of hearing people” (Harris & Bamford, 2001, p.978). Although this research could be considered out of date, more current research has also found that deaf patients leave health care appointments with a lack of understanding of diagnosis and treatment, medication use, and/or side effects, or sometimes face misdiagnosis completely (Scheier, 2009; Sheppard, 2013). Barnett (2002), suggested that not enough is done to educate medical students and residents with the skills necessary to successfully communicate with deaf and hard of hearing patients. More recent research has supported this statement, concluding that the care provided to deaf and hard of hearing individuals is inaccessible and culturally incompetent (Keunburg, Fellingner & Fellingner, 2016; Hoang, LaHousse, Nakaji & Sadler, 2011; Scheier 2009). Education of sign language could be introduced in institutions such as healthcare, so to improve the experiences of deaf individuals attempting to access health care but who are experiencing communication barriers (Ubido & Huntington, 2002). Although this issue was not acknowledged by the participants of the current study, other literature investigating this topic, such as those referenced above, has highlighted that more should be done to educate healthcare professionals on effective ways to communicate with deaf and hard of hearing individuals.

Haong et al. (2011) suggest that training medical staff on how to provide competent care to deaf and hard of hearing individuals would “significantly increase their capacity to care for community members and reduce the health disparities experienced by this community” (p.175).

The education system could also aim to increase awareness of the barriers faced by this population through making hearing children aware of the implications faced by the minority group and encouraging inclusivity. The education system could also incorporate sign language into their curriculum so to provide communication means between the deaf and hearing population other than spoken language. Jambor and Elliott (2005) found that an ideal school environment would assist deaf and hard of hearing students in developing skills necessary to communicate effectively with the hearing majority, whilst also helping them to identify with the Deaf community. Schools should aim to be this ideal environment, by encouraging means of communication between the two populations, and educating both populations of the values of Deaf culture. Watson, Gregory and Powers (1999) found that approximately 85% of deaf students are educated in mainstream schools – which, providing this is still a relevant finding today, suggests that interventions such as these would improve the experiences of school significantly for many deaf individuals. Also, by facilitating good communication conditions between the deaf and hard of hearing population and the hearing population, education providers can promote psychological empowerment, and lay good foundations for the development of quality of life (Hintermair, 2008). Considering the findings of the current study, we can see that both participants expressed feelings of isolation, as well as frustration and embarrassment when experiencing barriers to verbal communication with others (i.e. family, friends and work colleagues). If this application was put into place, individuals would be aware from a young age of effective strategies of communicating with deaf and hard of hearing individuals, and therefore this population may have more positive experiences in their communications with others.

Conclusion

In conclusion, the current study, which aimed to investigate individual experiences and perceptions of what it means to an individual to be deaf or hard of hearing, found three master themes across participants data. Firstly, aids don't always aid, with the emergent

themes amplifying the ‘wrong’ sounds, a visible reminder, and isolation, which highlighted some of the issues the participants experienced because of their hearing aids. Secondly, it’s not all negative, where participants expressed that their deafness can sometimes have some perks. And finally, relationships, with the emergent theme’s workplace relationships and familial relationships, where participants discussed how their experiences of being deaf or hard of hearing has affected their relationships with others. One conclusion that can be drawn from the data is that more research should be conducted in this area in a similar, participant driven and inclusive way. Although previous literature has used similar methods to investigate experiences of other disabilities (Hughes et al.,2019; Jespersen et al., 2019), the current study focuses solely of deafness. Use of this method when investigating the deaf population should be used in future research, to ensure an underlying framework of inclusivity and empowerment. Data may also be more credible when collected in this way, as it will not be tainted by any influence from researchers leading the discussions.

As well as this, more could be done within society to improve the experiences of deaf and hard of hearing individuals. This may be done by improving training within services such as health care to cater for the communication barriers that may be experienced by the deaf and hard of hearing population, as well as considering teaching sign language in schools in order to educate people from a young age on how to effectively communicate with this population in order to reduce discrimination and promote inclusivity.

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