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Moving forward with dignity: Exploring health awareness in an isolated Deaf community of Australia

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Abstract

Background: Those within the Deaf community are disadvantaged in a number of aspects of day-to-day life including their access to healthcare. At times, they may encounter barriers to healthcare even before they reach the consultation room. As a consequence, they may receive insufficient and inappropriate healthcare which may lead to poorer health outcomes.

Objective: A study was conducted to explore health awareness and access to health information and services of Deaf people living in Tasmania, Australia and identify ways of enhancing the interaction between the Deaf and the wider community.

Methods: A questionnaire was administered, including a number of demographic, health awareness and health service usage questions. In addition, semi-structured interviews and focus groups were conducted with service providers and the Deaf community between March and August 2014. An interpreter was present to translate the questions into Auslan and who then translated the Deaf participant's discussion into English for the researcher. Data were then analyzed using research software SPSS v20.0 and Nvivo 10.0.

Results: Health as a concept was poorly understood, including mental health, sexual health and health concerning alcohol and drug abuse. Regarding healthcare resources, due to a sense of security, trust and confidence, the family physician or general practitioner was the single most important health care provider among the Deaf.

Conclusions: The Deaf remain underserved by the current healthcare system; however, through resourcefulness and life experiences, the Deaf have developed coping and management strategies to move forward with dignity in education, meaningful employment and health access.

Keywords: Deaf, health, access, awareness, equity

Introduction

In Australia, the 'Deaf' (with capital D) are those people who identify themselves as members of the signing Deaf community and being 'culturally Deaf'.^{1, 2} Those who are deaf (with a lower case d) is used to describe people who have a physical condition of hearing loss of varying degrees irrespective of which communication mode they use.^{1, 2} The Deaf are individuals who use and share Australian Sign Language (Auslan), culture, traditions, rituals, social behaviours and a history of common experiences.³⁻⁵ They are more likely to have been born deaf early in life, are pre-lingually deaf and use sign language as a primary or preferred communication mode.^{1, 2} Auslan is a unique language, based on British Sign Language, which has its own distinct sentence structure, grammar and cannot be spoken or written.^{6, 7} With this distinctive language, the Deaf do not see themselves as having a disability, but rather as having a different way of communicating.⁶

Auslan is an independent language, but continues to be influenced by English, which is a second language for many Deaf. There is a misconception that the English written word is well understood by the Deaf.^{8, 9} The fact is English literacy is often poor⁸ among the Deaf due to lower education levels which negatively impacts their health literacy or their ability to acquire, process and understand health information. As a result, their personal empowerment, self-efficacy, autonomy and health also suffer.^{3, 10} In addition, social stereotyping of the Deaf as 'disabled' may lead to misconception, prejudice and possibly discrimination. Due to expressive and receptive communication differences, the Deaf tend to communicate and interact among themselves in a socially restricted environment, and Deaf culture is not widely understood or fully integrated in the hearing community.¹¹

This social isolation marginalises the Deaf. They are thus disadvantaged in many aspects and face barriers to healthcare even before they reach the consultation room.^{9, 12, 13} Consequently, the Deaf community at times may receive insufficient and inappropriate healthcare for their needs and thus

remain underserved by the healthcare system, which leads to poorer health outcomes and increased morbidity and mortality.³

The communication barriers with the wider community can also lead to poorer personal empowerment, social inclusion, self-efficacy and autonomy. It may also lead to low self-esteem, symptoms of anxiety, depression and greater mental health issues, leading again to poor healthcare access and a greater risk of poor health.^{3, 6, 8, 12, 14-16}

There have been a number of national and international studies concerning the health and social needs of the Deaf.^{5, 11, 17-21} However, there remains very little research within the Deaf community and little understanding the Deaf community's knowledge, perspectives, and beliefs about general and mental health issues in Tasmania, Australia.^{11, 16}

Within this context, this study aims to examine the healthcare issues facing the Deaf community in Tasmania, particularly through their own voices. The study sought to explore the health awareness of Deaf people living in Tasmania and identify ways of enhancing the interaction between the Deaf and the wider community, particularly with regard to accessing health information and services.

Methods

Setting

The research was conducted in Tasmania, which is a small island state off the south east coast of mainland Australia with a population of over 500,000.²² Currently, there are approximately 299 people who use some form of sign language within Tasmania with the majority (85.6%) using Auslan as their first language across the North and North West and South of Tasmania.²² Tasmanian Deaf community represents only 3% of the total Deaf population in Australia (9,935) and are geographically isolated from the remainder of the population.²²

Currently in Tasmania, there are two services that provide Auslan interpreting services. These services include the National Auslan Interpreter Booking and Payment Service (NABS) which is funded by the Australian Government to provide free interpreting services for private health care appointments.²³ The second service is the Tasmanian Deaf Society (TasDeaf), who under the auspice of Sign Language Communications Victoria undertakes interpreting services for all other needs among the Deaf community.²⁴

Design

A mixed method approach was undertaken and was framed by a concurrent triangulation design which is one of the more simple mixed method designs where priority is neither given to the qualitative or quantitative methods that are used.²⁵ Using this approach allows all qualitative and quantitative data to be collected separately, yet concurrently, which are then combined at the interpretation stage of the study.²⁵⁻²⁹ The rationale for this approach was to ensure that findings within the single study are corroborated and substantiated in a meaningful way.²⁵

Mixed method paradigms used by health researchers are increasingly pragmatic in their approach, yet the standpoint, perspectives and assumptions of the researchers within this study were from an

interpretivist or constructivist position, from where phenomenological traditions stem.^{30, 31} Within the study, phenomenological approaches were used as the vehicle to understand the everyday subjective experiences of the lived world among members of the Deaf community. It is through these insights that a greater understanding is achieved regarding the Deaf's experiences and how these experiences impact their health and wellbeing.³²⁻³⁶

Data were collected using a questionnaire, semi-structured interviews and focus groups. Initial data were collected from both hearing and Deaf service providers. Data were also collected from the Deaf community through a questionnaire, focus group discussions and face-to-face interviews. Due to the ease of identification of individuals in such a small community, much of the identifiable demographic data were not collected.

Instruments

The questionnaire was developed and customized from the publically available questionnaire developed by Steinberg, et al.¹¹ The questionnaire was administered as part of a health project that was provided to the Deaf community between June and November 2014. A number of questions that explored demographic background, health awareness and health service usage were asked and included education, income, employment status, the ability to communicate and be understood within the hearing community, the last visit to their general practitioner and the services they used when seeking care. (Appendix A)

The semi-structured interviews and focus groups were conducted between March and August 2014. It involved seven key questions for service providers and nine key questions for Deaf participants. Interview and focus group questions were based on and customized from the study conducted among the Deaf community in the US developed by Steinberg, et al.,¹¹ and specifically designed for Deaf with limited literacy and English is a second language. (Appendix B)

Each interview or focus group was between 30 and 90 minutes and was audio recorded and/or video recorded with the permission of each participant. Among those service providers who were deaf and other Deaf participants, an interpreter was present to translate the questions into Auslan and who then translated the deaf participant's discussion into English for the researcher. The interviews and focus group data were subsequently transcribed into a Microsoft Word document and each interviewee was provided with a transcript and invited to edit, change or add information to the transcript as required.

The project received approval from the Human Research Ethics Committee (Tasmania) Network (H0013768).

Recruitment

Service providers

A purposeful sample of five staff members from TasDeaf and NABS that consist of less than 15 individuals were invited to participate in the interview to provide information related to the history, insights, meaning and experience of the Deaf community. The interviews focus on the richness and depth rather than the breadth of information. As these participants are in close contact with the Deaf community, they have rich contextual information which would add to the depth of study. Among the five service providers that were interviewed, two were Deaf. The remaining three were interpreters for the Deaf. Among them, one was a hearing parent of adult Deaf children who had worked in the industry for more than 25 years, while the remaining two were hearing and had been working with the Deaf community for more than 15 years.

Deaf participants

These participants are those within the Deaf community and recognize themselves part of the Deaf culture in the Northern, North Western and Southern areas of Tasmania. Using focus groups is consistent with the Deaf culture. Gatherings are considered opportunities for sharing information.

All Deaf participants were informed about the health project invited through service providers via letter, flyers and the bimonthly newsletter and directly asked to participate. Those that attended the project were invited to complete a questionnaire and participate in a focus group or interview.

Special considerations

The research needed to be designed to minimise any possible risks to participants. The information sheets, consent forms, questionnaire and interview questions were provided in English which is considered a second language whereas English literacy among the Deaf is often poor. Thus it was vital that the Deaf participants had a fair understanding of basic English to read and comprehend the materials provided. To address these issues, the information sheet and consent forms were written and assessed at the Flesch-Kincaid score Grade 7.4 and Grade 7.1 level respectively. To verify and validate these documents, consultation with the Deaf community was gained.

It must be noted that the principle researcher is hearing, however, was able to use and understand Auslan because as a child of a Deaf adult (CODA), it is his first language. He has grown up within and as part of the Deaf culture and in this way, he is distinctively placed to understand and have special consideration for those within the Deaf community. However, interpreters were used to reduce bias and ensure correct understanding of what the Deaf were saying.

Data analysis

The transcribed raw data were cleaned and imported to NVivo 10 software used for data collation and coding. Grouped data were subject to double checking to ensure the integrity of the information. Each participant was coded based on information such as being Hearing or Deaf, a service provider or participant of an interview or focus group. They were then assigned a numerical code based on the order in which they provided information by interview or focus group. For example, a service provider would be presented as "Service provider 2 – Hearing" and other participants would be presented as "Focus group participant 1 – Deaf."

Data were then thematically analyzed to systematically identify recurring themes, behavior and experiences arising from the interviews and written responses within the questionnaires.³⁷⁻³⁹ In addition, these themes are viewed in the context in which they were developed, which allows the identification of new or emerging themes.^{37, 39-41} The process of thematic analysis is to assemble the singular, small and at times meaningless ideas or experiences from individuals, which when combined with the experiences of many other individuals creates a wider understanding of a phenomenon.^{37, 41} Inferences can then be made from the rich data and how these relate to the literature which forms a tapestry of findings, interpretations and conclusions.^{37, 39, 40}

The questionnaire data were entered into SPSS v20 and analyzed to ascertain and present findings from the various quantitative responses.⁴² Due to the small number of participants, inferential statistical techniques were not employed to determine the significance of the results. In this case, simple descriptive statistics were used to present data in a way that was both informative and meaningful. This included frequency and proportion for categorical or ordinal data.⁴³

Results

In total, 17 Deaf participants completed the questionnaire, and 21 Deaf individuals were interviewed. Five additional interviews were conducted with service providers who were working with the Deaf at various sites across Tasmania.

Questionnaire findings

The low questionnaire response rate may be reflective of the low attendance to the health project by members of the Deaf community. The researchers and interpreters were heavily relied upon by the participants to understand the wording of the questionnaire. In each instance the questionnaire was completed, the interpreters were required to translate the questionnaire into Auslan for the participants to understand. Posting the questionnaire out to each member of the deaf community was therefore abandoned.

Demographic information

Within the small cohort of questionnaire participants, it was shown that eight (47.1%) respondents were male and nine were female (52.9%) and the mean age was 57.9 years old (ranging from 22 to 82 years old). Six (35.3%) had profound hearing loss, and six (35.3%) had severe hearing loss, while five (29.4%) were unsure. Six (35.3%) participants were born hearing and lost their hearing at a young age, while the remaining 11 participants (64.7%) were born deaf.

Four Deaf (25.0%) did not complete high school, while a similar proportion did. Seven (43.8%) had achieved an apprenticeship or vocational training and one even attended university. The majority of participants were or had been employed in manual or unskilled labor, which may have impacted directly on income levels. Specifically, 11 (68.8%) participants were living on low income levels; one (6.2%) was a middle income earner while the remaining four (25.0%) did not want to disclose their income levels. It should be noted not all participants completed this section of the questionnaire.

Communicating and interacting with the wider community

In addition to the general demographic information, it was shown that eight (46.2%) of the participants were not comfortable communicating with hearing people while eight (46.2%) said that hearing people would give them trouble or be unkind due to being Deaf. In addition, it was shown that 15 (88.2%) of participants prefer to spend more time within the Deaf community where they felt safe to communicate and share common interests and culture.

Health service access and usage

In the past 12 months, 14 (82.4%) participants indicated that they had visited their Family physician or General Practitioner (GP), which is lower than the state average (85.4%), but higher than the Australian national average (80.9%).⁴⁴ In addition, only seven (41.2%) had a complete physical examination in this same time period. It was shown that there were a number of methods that were used when interacting with their GP. For example, seven (41.2%) used Auslan and an interpreter when visiting their GP, five (29.4%) lip-read and 11 (64.7%) used writing notes in English to communicate when seeking care.

In addition to seeing the GP, it was also shown that four (23.5%) had a hospital stay and over eight (47.0%) had visited an emergency room in the past twelve months. These results were much higher than the Tasmanian and Australian national averages, where 13.9% and 13% had been admitted to hospital in the past 12 months and 16.5% and 14% had visited an emergency room in the past 12 months respectively.⁴⁴ Also it was found that 15 (88.2%) participants had never used services such as mental health, sexual health or drug and alcohol service at any time. The findings for mental health were similar to the Australian national average 12% who had accessed mental health services in the past 12 months.⁴⁵ However, these service usage rates may be reflective of the inability to access these services, a lack of awareness of the services; or the principle care being sought through their GP where they have a long term relationship and established trust.

Focus group and interviews

In addition to the questionnaire data, a focus group was conducted with 10 Deaf individuals, while 11 interviews were conducted with other Deaf people. The participants included 13 females and eight males state-wide, ranging in age from early 20s to 80s. As outlined, five additional interviews were conducted with service providers who work with the Deaf. Two of the five service providers that were interviewed were Deaf themselves.

Health awareness

Among the Deaf, there was a lot of discussion around what health meant and navigating the health system as a Deaf person. For example, when discussing about health, many Deaf had difficulty identifying, explaining and expressing what health actually was. After some discussion and examples, there was consensus that health meant many differing things to each Deaf participant. Overall, the meaning of health among the Deaf was about how to maintain good health. Examples included eating good food, exercise, sport, gardening, reading food labels and following a strict health regime. In most cases, there was a dichotomy of language used among Deaf participants, such as do's/don'ts, good/bad and strong/weak.

When asked about where they learned about health and being healthy, the responses were mixed. The younger participants stated they had learned a lot from parents, from school and from friends. Conversely, the older participants stated they often had to learn for themselves. This was demonstrated when an individual did not know what to do if a health issue occurred and learned from the experiences they had. They stated

I broke my collar bone while at the boarding school and I didn't know what to do. I didn't tell the boarding school... until the next day one of [teachers] saw I had a sore arm and they took me to the hospital... we didn't learn anything at school. (Interview participant 3 – Deaf)

There were very few participants who knew about other health services in the community, other than the hospital and their own GP. It was stated that a few come into TasDeaf to seek assistance with health issues such as sexual health matters, however “a lot go undiagnosed” (Service interview participant 1 – Deaf).

Mental health

Beyond the issues of health awareness, mental health was raised as a major issue among the Deaf.

Mental health is big thing too – a very big thing as there is quite a lot here have mental health issues. (Service interview participant 1 – Deaf)

Poor mental health was suggested that it may be from a number of issues experienced among some of the Deaf, such as isolation, the challenges of mixing with hearing people, “being bullied when younger” (Service interview participant 1 – Deaf) and being “frustrated with everything that is going on around them... and how do they cope” (Service interview participant 4 – Hearing).

The challenge was the inability for the Deaf community to access adequate health services. It was highlighted that ambulance, police and health services required further education concerning the needs of the Deaf. One service provider gave a poignant example of the lack of understanding among health services and health services inadequately meeting the needs of a Deaf client.

I had one [Deaf client]... he came here and I had to call the ambulance as he was suicidal. He went in the hospital and they sent him home. Later, he committed suicide. (Service interview participant 1 – Deaf)

It was highlighted that when experiencing both mental and physical health issues, other than TasDeaf, a Deaf person’s GP was the single most important health care provider. There was a sense of security, trust and confidence with their family health care provider.

Accessing interpreting services

Despite the trust and confidence in the GP, one Deaf participant highlighted there was a number of issues and challenges that the Deaf encountered when accessing interpreting services to communicate adequately with health services. It was highlighted that there were only one full time position and two casual interpreters employed through NABS to provide interpreting services across the whole state and all three were based in the Capital city. Additionally, TasDeaf interpreters had recently ceased being employed by TasDeaf and were all working in a casual capacity.

From the perspective from the Deaf community, there were some mixed responses regarding access to interpreting services. Some of the comments included

If there is no interpreters it is frustrating as you always have to write things down and it is not a good way – I would rather have an interpreter as it is so much easier to understand a person. (Focus group participant 1 – Deaf)

However, it was also highlighted that some of the Deaf chose not to access any of the interpreting services. One participant stated

I don't want them [service provider for the Deaf] to think that I am poor and deaf and that I need help. No, I am strong, I stand up and I can do it myself. If I have a health problem, I will never call to interpreting services... I have my own way. (Interview participant 3 – Deaf)

Within the discussion with this Deaf participant, there was a level of resilience that had been developed throughout their life and learning how to cope on their own and was observed among other Deaf participants. For this particular individual, there were some challenges in the past which had an impact on current behaviors when accessing interpreting services.

If I am sick, I call [interpreter service] and they say sorry all interpreters are booked I will have to wait a few days for one. No way! I told them to forget about it. (Interview participant 3 – Deaf)

Although there was frustration with interpreting services, it was later revealed that the frustration and annoyance was with the unequal access to services that the hearing community had. A participant stated

The Deaf always have to wait... people who are hearing they can go straight away and have access to services. It isn't fair, why are we left last? (Interview participant 11 – Deaf)

Coping strategies

Beyond being able to access and communicate with the health services and the wider community, it was highlighted that the Deaf were more resilient and had developed many of the skills to manage and cope with the disadvantaged circumstances. This was pointed out when one participant stated they needed to develop their own confidence

I had to develop my own confidence. I was the only deaf person at [high school] at that time and so I had to develop that confidence myself and I had to build it up. I had to open up to have many hearing friends. (Interview participant 2 – Deaf)

This view was in contrast to some of the older Deaf participants who had a more difficult time at school, however, were shown to develop resilience and skills to learn and cope in the wider community. Some comments included

My schooling was very poor... they didn't the deaf about life or what works best. I didn't learn about life, nothing. I had to learn life myself the same as all the Deaf – they had to learn and find out for themselves. (Interview participant 5 – Deaf)

Despite these challenges, the Deaf learned to develop the requisite skills to manage and function within the wider hearing community, as indicated by a service provider.

Deaf people will always find their way around the barriers they encounter. They have always have done and always will do, but in today's world there shouldn't be any barriers. (Service interview participant 2 – Hearing)

Technology

In many circumstances, technology was identified to improve access, as a means of coping and improving communication with health providers, the wider community and among the Deaf. With the advent of greater advances in mobile phone, computer technologies and the Internet, communication has become easier and more accessible to the Deaf community. The greatest impact on communication between the hearing and the Deaf was indicated to be Skype and Face Time, Facebook and the use of SMS with mobile or cellular phones.

Despite the advances in technology, there were a number of comments that pertained to the challenges associated with technology. Two service providers highlighted that technology has improved communication, but had decreased face to face and social group interaction. They stated

In the old days the deaf community was a strong community like family who knew each other all their lives... that is the down side to technology – they don't seem together like that anymore. (Service interview participant 5 – Hearing)

Traditionally the deaf would come and congregate... it was about getting together, talking and being relaxed about their language. Technology has taken away that social side and the language. They are not as cohesive as a group anymore. (Service interview participant 2 – Hearing)

It was stated that technology, although a useful tool, was reducing the need for Deaf people to come together, to share their language and their culture and participating within the cultural community of shared values and experiences. This reduction in the community coming together as a group was caused by having alternative communication methods and has an impact on isolation, language, identity and mental health.

Discussion

The study aimed to examine the issues facing the Deaf community in Tasmania and explore their health issues and identify ways of enhancing the interaction between the Deaf and the wider community, particularly with regard accessing health information and services. It was particularly vital to gain these insights through their own 'voices'.

Equity and fairness were an overarching theme, particularly around having the right to desire and seek further education, meaningful employment and access to interpreters to ensure other aspects of life were 'fair', which has been highlighted among other Deaf communities across the globe.^{17, 46, 47}

This included equity around health and accessing health services. It was noted that the percentage of participants who visited a GP were similar rates to national and state averages; however, emergency room attendance was much higher among the participants. This may be reflective of a number of factors such as understanding of the health system as whole, or inability to obtain timely access to GPs including interpretive services.

However, it was recognized that health as a concept was poorly understood and this may have some impact on overall health literacy, as has been similarly observed among other Deaf communities, such as South Africa, the UK and the US.⁴⁶⁻⁵¹ Concepts such as mental health, alcohol and drugs, and sexual health are not well known within this cohort and was demonstrated when the Deaf commented throughout the research process that they 'did not know this' or 'did not know that' such as cancer, STIs or other illnesses.⁴⁶

It was recognized that all of the Deaf had developed key skills strategies to manage their health and they had key health care providers and communication strategies that they used if they were unwell. Often the strategies centred on the GP being the key health provider and a mother, hearing partner, interpreter or technology that provided assistance with communication, yet as shown elsewhere these interactions do not always lead to health needs being addressed adequately.^{48, 50, 52} Many of

the Deaf used interpreters and also advocated with their health care providers to have access to interpreters when seeking care. However, some Deaf, due to poor experiences around timely access to interpreter, developed other avenues to seek care and function within the hearing community. These other approaches which have been shown, in the US still have an impact on poorer health encounters and health needs not being fully met.^{49,50} Among some of the study participants, it was trial and error, yet they had developed the skills to be self-sufficient and to cope with whatever challenge they faced.⁴⁶

Meeting challenges was shown to be further reinforced through new and emerging technologies to meet the demands that the Deaf encountered on a day to day basis. Technologies were embraced by most of the Deaf to improve communication with each other and the wider community and have been observed among other Deaf communities globally.^{50,52} However, it was shown that one of the downsides to greater communication through technology was the diaspora of the Deaf as a socially cohesive community, which was shown to be quite different to other deaf communities where technology had enhanced community cohesion. In Tasmania, there were pockets where some of the Deaf met regularly however, in other areas of the state, there was a real lack of social cohesion and commitment to the Deaf as a group, despite being able to communicate instantly and regularly. This new phenomenon of technology was felt to have an impact on social interaction, language, identity and overall mental health.

Limitations

The key limitation of the study was the lack of interest from the Deaf community. For example, there were a high number of invitations and reminders sent out regarding Health project; however, very few attended. Future events and projects will need to be adjusted to meet the needs of the Deaf. Such as evening sessions and activities that involve a more social element within health projects. In addition, future development of the questionnaire's wording is required to ensure its efficacy among

other Deaf communities, while examining further avenues to increase participation. Although these findings are not generalizable, they provide insights into Deaf communities that may be isolated from the larger Deaf populations.

Conclusion

The Deaf are a linguistic minority that live and work within the greater community. They have social and educational needs, employment aspirations and health concerns much like those of the hearing community. However, as part of this study, it has been highlighted that the Deaf as a community have undergone substantial issues and challenges both within education, employment and health care access. Deaf community at times may receive insufficient interpreting services that may lead to inappropriate healthcare for their needs. In their current situation in Tasmania, they remain underserved by the healthcare system.

Nevertheless, the study has shown that through resourcefulness and life experiences, the Deaf have developed coping and management strategies to move forward with dignity. This study has provided a snapshot into this specific community where little research has been conducted before while providing some insight into the challenges that may be experienced by other small Deaf communities. As such, additional research is recommended to further investigate, internationally, the health needs of other Deaf communities and to specifically examine the strategies used to ensure adequate health care is received in an accessible and acceptable manner.

An additional and unexpected outcome of the study was that poor education and employment opportunities were a large concern beyond health within the Tasmanian Deaf community. Overall, post-secondary school education among the Deaf has been shown to improve economic earning potential and reduced dependence on federal support programs, such as unemployment and disability pension for sources of income.⁵³ As a result additional funding should be sought to ensure

adequate support so that education services are enabled to meet the needs of the Deaf community, particularly among those who seek to undertake post-secondary education.

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