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Research Paper

# 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 health care. At times, they may encounter barriers to health care even before they reach the consultation room. As a consequence, they may receive insufficient and inappropriate health care 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 health care 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 health care 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

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 behaviors 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 poor 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 marginalizes the Deaf. They are thus disadvantaged in many aspects and face barriers to

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health care even before they reach the consultation room.[9,12,13] Consequently, the Deaf community at times may receive insufficient and inappropriate health care for their needs and thus remain underserved by the health care 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 health care 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 health care 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 (9935) 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 qualitative 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 min 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