HEALTH STATE VALUES OF DEAF BRITISH SIGN LANGUAGE (BSL) USERS IN THE UK: AN APPLICATION OF THE BSL VERSION OF THE EQ-5D-5L

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ABSTRACT

Background

Deaf people experience health inequalities compared to hearing populations. The EQ-5D, a widely used, standardised, generic measure of health status which is available in over 100 languages, was recently translated into British Sign Language (BSL) and initial validation conducted. Using data from this previous study of the EQ-5D-5L BSL we aimed to assess (i) whether responses to the EQ-5D differed between a sample of Deaf BSL users and the general population (ii) whether socio-demographic characteristics and clinical measures were associated with EQ-5D index scores in Deaf BSL users and (iii) the impact of psychological distress and depression on health status in Deaf BSL users.

Methods

Published population tariffs were applied to the EQ-5D-5L BSL, using the crosswalk methodology, to estimate health state values. Descriptive statistics (mean, SD, 95% CIs) compared Deaf BSL signer participants' (n=92) responses to data from the general population. Descriptive statistics and linear regression analyses were used to identify associations between Deaf participants' EQ-5D index scores, socio-demographic characteristics, physical health and depression. Descriptive statistics compared the BSL index scores for people with psychological distress/depression to those from two cross-sectional, population-based surveys.

Results

Using the EQ-5D, Deaf participants had lower mean health-state values (0.78; 95% CI 0.72 – 0.83; n=89) than people participating in the 2017 Health Survey for England (0.84; 95% CI 0.83 – 0.84; n=7,169). Unlike larger studies, such as the Health Survey for England sample, there was insufficient evidence to assess whether Deaf participants' EQ-5D health state values were associated with their demographic characteristics. Nevertheless, analysis of the BSL study data indicated long-standing physical illness was associated with lower health-state values (OLS coefficient = -0.354; 95% CI -0.484, -0.224; $p < 0.01$; n=82). Forty-three percent of our Deaf participants had depression. Participants with depression had reduced health status (0.67; 95% CI 0.58 – 0.77; n=36) compared to those with no psychological distress or depression (0.87; 95% CI 0.61 – 0.67; n=36).

Conclusions

The study highlights reduced health in the Deaf signing population, compared to the general population. Public health initiatives focused on BSL users, aiming to increase physical and mental health, are needed to address this gap.

Key points for decision makers

- This is the first study to investigate health state values in the Deaf population. Deaf BSL users more commonly report health difficulties on the EQ-5D dimensions and typically have lower EQ-5D index values, when compared to the general population.
- Depression is prevalent within the Deaf population which has a key impact on health status as measured by the EQ-5D.
- The current evidence base for the Deaf population is minimal and further research is needed to identify priority areas, to improve health, and to ensure cost-utility analysis using population specific values are feasible for this population.

COMPLIANCE WITH ETHICAL STANDARDS

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AY declares funding from the National Deaf Children's Society, as well as current and previous funding from the AHRC, MRC, GCRF, NIHR and NHS England within the last 3 years, related to research in the Deaf population. LMD declares funding from the MRC, ESRC, NIHR, Department of Health and Cancer Research UK, some of which relates to research in the Deaf population. KR declares current funding from the NIHR and National Deaf Children's Society, as well as funding from the AHRC, Department for Education and NIHR in the last 3 years, related to research in the Deaf population. GES and SD declare that they have no conflict of interest.

Research involving human participants and/or animals

This study performed a secondary analysis of existing data and thus no participants were recruited. In the prior study, from which the data were taken, ethics approval was received from the University of Manchester Research Ethics Committee (REC) (reference number: 14183). All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. This article does not contain any studies with animals performed by any of the authors.

Informed consent

In the prior study, all participants who completed the EQ5D-5L BSL gave individual informed consent and that they gave consent for secondary data analysis of anonymised results, ethics approval was received from the University of Manchester Research Ethics Committee (REC) (reference number: 14183).

AVAILABILITY OF DATA AND MATERIAL

The datasets analysed during the current study are available from the corresponding author on reasonable request.

1. INTRODUCTION

It is estimated there are 87,000 Deaf people in the UK who use British Sign Language (BSL) as their first, preferred or only language (BSL) [1]. In common with other language using communities, Deaf people who sign claim a distinct cultural-linguistic identity, usually marked by the use of capital 'D' (Deaf). This is to distinguish this population from the larger number of people who have acquired hearing loss, those who use spoken language and for whom deafness is primarily regarded as disability and impairment [2]. The UK government finally formally recognised BSL as an indigenous UK language in 2003 [3] and its legal status was enhanced in Scotland through the BSL Scotland Act 2015 [4] which confers specific duties on public sector organisations to promote equality, including those associated with health and social care, as well as conferring new rights to combat discrimination on the basis of sign language use.

Deaf people experience health inequalities compared to hearing populations, whether in terms of access to services, general health or outcomes following health interventions [5–8]. Key contributors to such health inequalities include ineffective communication strategies between Deaf people and health professionals, poor health literacy amongst Deaf people and inadequate health surveillance [9–11]. Health conditions such as obesity, heart disease and diabetes are high in Deaf populations [6, 12]. Common mental health problems, including anxiety and depression, are also high within Deaf populations in comparison to their hearing counterpart [8, 13]. Kvam et al. (2007) found that the prevalence of anxiety and depression is 33% (measured using the Hopkins Symptom Checklist, SCL-5, which captures symptoms of anxiety and depression in a single measure), which is higher than their hearing counterparts [8, 14].

The EQ-5D, a generic measure of health status, is available in more than 100 written/spoken languages and is translated into BSL, the first signed language version to be formally endorsed by the EuroQol Group [15, 16]. The English (UK) version of EQ-5D-5L was translated into BSL following an approved adaptation of the guidelines developed by the EuroQol group [16]. This was to accommodate the entirely visual nature of BSL as a language. The translation work included two bilingual (BSL and English) translation teams (forward translation and back translation teams) who translated from their second language to their first language. Stages of translation were filmed, and were used to identify discrepancies, discuss these within the team and refine the translation. Cognitive testing interviews with 8 Deaf people and 11 bilingual Deaf people were conducted; these showed the content of items in the BSL version to be equivalent to the English version. Ninety-two Deaf people who use BSL in the UK were surveyed with the aim of assessing the validity and reliability of the EQ-5D-5L BSL. Participants were also asked to complete the CORE-10 BSL and CORE-6D BSL. The CORE-10 is a short measure of psychological distress; the benefits of the measure are that it is easy to use for common presentations of mental health conditions and was available in BSL [17]. The survey was designed in SelectSurvey which allows for embedded videos. The inclusion criteria were that participants must be adults (18+) and a Deaf BSL user. Deaf people were recruited Deaf community networks using email, social media and online message boards, where information about the study was provided in both BSL and English. All survey materials were available in BSL, with contact details for a native BSL user if participants had questions. Analyses included using Cronbach's alpha values to assess internal reliability, interclass correlation coefficients (CC) and weighted kappa scores to assess re-test reliability, and Kandall's tau to assess convergent validity. The analyses suggested that the psychometric properties of EQ-5D-5L BSL were good. This study was, however, a first step, and further larger studies are needed to collect more data to assess the validity of the EQ-5D in this population. The initial results from the study also suggested that the participants had a range of health problems [16, 18]. In light of the evidence suggesting that Deaf people have poorer general health and mental health than the hearing population [5–8, 12, 13, 16, 18], this paper reports additional, post-hoc analyses of the data to explore the impact of being Deaf on health related health status in more detail. Note that we focus specifically on Deaf BSL users (signers), rather than the wider population with hearing loss who use spoken languages.

Our research questions were:

1. What are the EQ-5D responses and index values for the sampled Deaf population and how do these compare to values for the general population?
2. Which participant demographics and health symptoms are associated with EQ-5D index values in the Deaf population?
3. How do EQ-5D index values vary between Deaf people with and without psychological distress and how do these compare to published figures for the wider population?

2. METHODS

2.1 Data

The data collected from UK residents as part of the EQ-5D-5L BSL translation and validation study (described in the introduction) were used to address the research questions for Deaf people [16].

Data from the Health Survey for England (HSE) 2017 were used to estimate general population values for our analyses [19]. The general population will include people with and without hearing difficulties but is very unlikely to include members of the culturally Deaf population. The methodology for HSE is described elsewhere and copies of disclosure-controlled datasets which do not identify individuals are available for specific research projects through the UK Data Service [20, 21]. The HSE 2017 had a 60% response and includes demographic and health data from 7,997 adults living in private households in England. We used the HSE interview weight to account for selection and non-response biases [20]. Data collected includes the EQ-5D-5L, health state index value and EQ-VAS, participant-reported long-standing illness and long-standing mental health conditions [22]. The HSE also collects information for children, which were excluded from our analysis.

2.2 Calculating the EQ-5D index scores

Index values were calculated from the EQ-5D-5L BSL for all Deaf participants who completed the measure in the BSL translation and validation study and the English EQ-5D-5L for HSE participants, at the first time point, using the published crosswalk system. The crosswalk system was developed through a study that administered both the EQ-5D-3L and EQ-5D-5L; 3L responses were predicted from 5L responses following which probabilities associated to 3L responses were applied to generate a health state value for the 5L response [23]. It has been used since 2012 to calculate health state values (index scores/values) from EQ-5D-5L data and is recommended by NICE [23–25].

2.3 Comparison of health state values of Deaf people with general population values

Descriptive statistics were used to summarise the responses of Deaf people for the EQ-5D dimensions (percent (%) reporting at each level). The EQ-5D derived index values and EQ-VAS (mean, 95% confidence intervals) collected in the BSL study of the Deaf population were compared to the general population using the HSE dataset. Both datasets collected the 5-level version of the EQ-5D. To facilitate comparison Deaf participant data was compared to to HSE, by age and gender. The BSL inclusion criteria were for adults aged 18+, whereas the HSE data is 16+, in addition, the HSE data included individuals aged 75+ whereas our oldest Deaf participant with a recorded age was 70. In addition, there were very small numbers of participants in the youngest and oldest age groups in the BSL study. Accordingly, these age groups have been combined and the youngest age category is defined as people who are less than 35 years old and the oldest age category is defined as 55 years or older.

2.4 Assessment of which participant characteristics are associated with health state values

Linear regression (ordinary least squares; OLS) was used to assess whether participants' socio-demographic characteristics, physical health and psychological distress status were associated with Deaf participants' health and EQ-5D index values. A significance level of 0.05 was used to interpret the results. The sample for the full model was limited by missing data about participants demographic characteristics. To use a greater sample of the data, a reduced version of the regression model was also tested, which excluded demographic characteristics and allowed us to investigate potential differences between participants with complete and incomplete data. The reduced model included a missing data indicator, to summarise and account for whether people had missing age, gender, ethnicity and/or employment (the demographic variables from the full model).

In line with clinical cut-offs from the hearing population a CORE-10 score of ≥11 was used to identify participants with psychological distress and a CORE-10 score of ≥13was used to identify participants with depression (note that cut-off values specific to the Deaf population are not available) [17]. Note that we also had the CORE-6D values available, which is a reduced version, however, we used the CORE-10 data as it included more items and response levels and has clear cut-offs for the interpretation of values [17, 26].

2.5 Comparison of health state values between people with and without psychological distress

Descriptive statistics (mean, standard deviation and 95% confidence intervals) were used to summarise the health state index values for our sample by whether or not they reported experiencing psychological distress or depression. We compared our analysis of EQ-5D index values for Deaf UK based participants to those found in two population based surveys [19, 27]. We assumed that the study samples in these surveys were likely to be the hearing population (with or without hearing difficulties) rather than including members of the culturally Deaf population. We used descriptive statistics (mean, sd) to compare the EQ-5D data generated values for Deaf people in the UK to those for the general population with and without psychological distress.

The data were analysed using Stata version 15.0 (Timberlake, London, UK). All analyses of HSE data used the Stata survey data analysis commands and the HSE interview weight to account for selection and non-response biases [20].

3. RESULTS

Full details about participants' demographic and health related characteristics used in the analyses are provided in the translation and validation paper for the EQ-5D BSL, an overview is included in Table 1 [16].

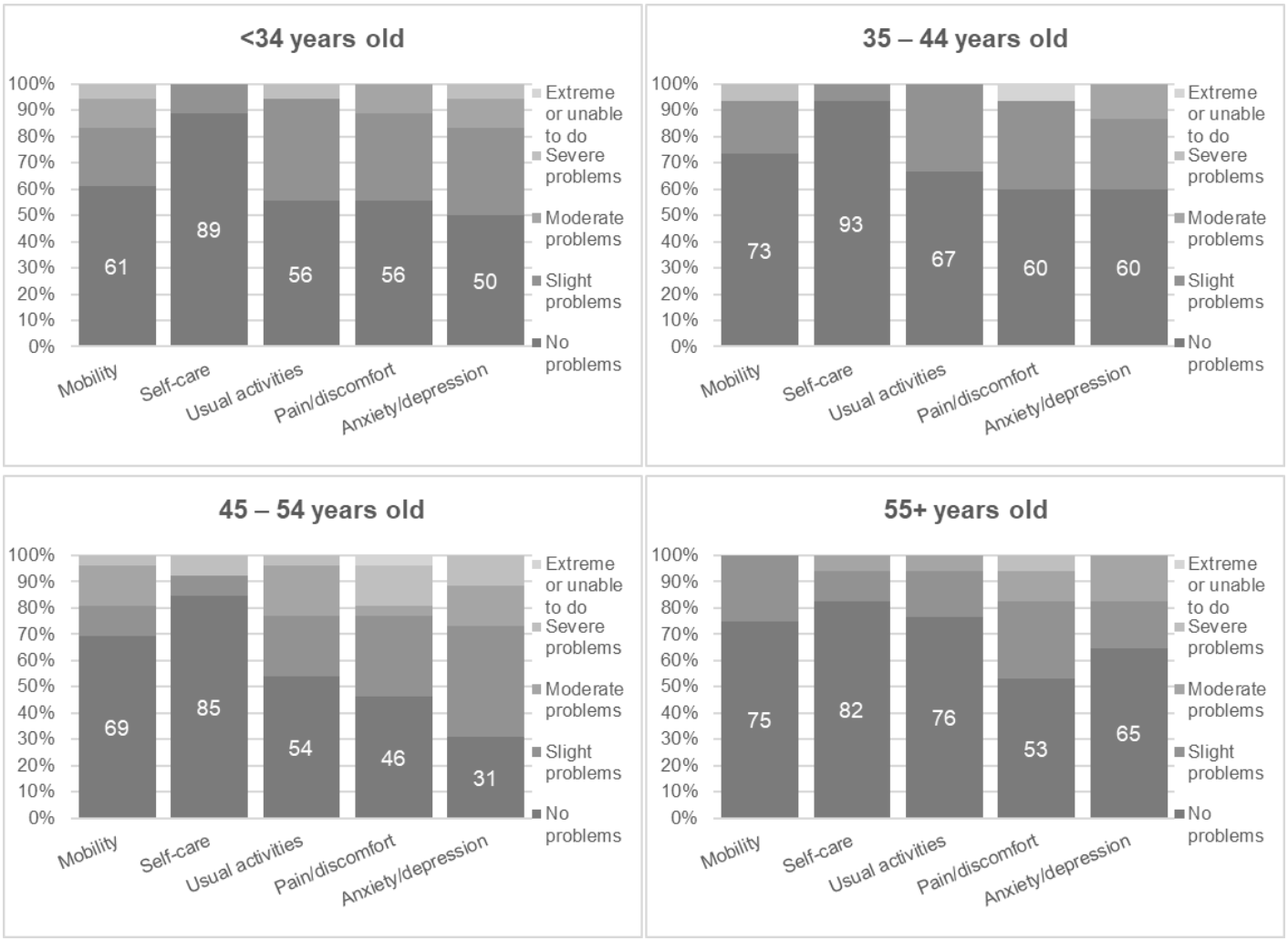
Table 1 Deaf BSL user participant demographics

Demographics		**Proportion of the population**
Gender	Female	64/92 (69.6%)
	Male	26/92 (28.3%)
	Missing	2/92 (2.2%)
Age	18-24	4/92 (4.3%%)
	25-34	14/92 (15.2%)
	35-44	17/92 (18.5%)
	45-54	26/92 (28.3%)
	55-64	14/92 (15.2%)
	65+	3/92 (3.3%)
	Missing	14/92 (15.2%)
Ethnicity	White British	71/92 (77.2%)
	Any other ethnicity	18/92 (19.6%)
	Missing	3/92 (3.3%)
Productive activity	Productively active (includes employment, education and housework)	73/92 (79.3%)
	Not productively active	14/92 (15.2%)
	Missing	5/92 (5.4%)
Disability	Considers themselves to have a disability	46/92 (50.0%)
	Does not consider themselves to have a disability	39/92 (42.4%)
	Missing	7/92 (7.6%)

3.1 Deaf participants reporting by EQ-5D dimension and level

In total, over 73% of Deaf participants reported some (slight to extreme) problems on one or more of the EQ-5D dimensions. For Deaf participants with complete data (n=89/92) across EQ-5D dimensions, the proportions reporting no problems were 70% mobility, 88% self-care, 63% usual activities, 49% pain/discomfort and 47% anxiety/depression. Figure 1 presents the proportion reporting across Deaf participants by dimension and level. The supplementary material includes a tabulated comparison between the Deaf participants in our sample and general population data from HSE.

Figure 1 Reporting across dimensions and levels (Deaf participants)



3.2 Comparison of EQ-5D responses and health state index values of Deaf people with the general population

The EQ-VAS score was 70.23 (95% CI 65.41 – 75.04; n = 88) for the sample of Deaf participants, which is lower than the mean score from the HSE data (79.15; 95% CI 78.68 – 79.62; n = 7,161).

EQ-5D index values by age group and gender for the Deaf participants and the general population (from HSE) are provided in Table 2. Most Deaf participants had lower health status when compared to the HSE data for their age group and gender. The overall mean index values were 0.78 (95% CI 0.72 – 0.83; n=89) for Deaf participants, lower than the HSE data for the general population (0.84; 95% CI 0.83 – 0.84; n=7,169).

Table 2 Mean EQ-5D index values by age group and gender

Age group	<34	35-44	45-54	55+	Total sample*
Female					
Deaf participants mean EQ-5D index value	0.804	0.759	0.756	0.840	0.766
95% CI	0.677 - 0.931	0.556 - 0.962	0.651 - 0.861	0.744 - 0.936	0.706 - 0.827
n	12	9	20	11	63
Health survey England mean EQ-5D index value	0.878	0.850	0.817	0.773	0.824
95% CI	0.866 - 0.890	0.834 - 0.866	0.798 - 0.837	0.761 - 0.784	0.816 - 0.831
n	874	718	706	1,750	4,048
Male					
Deaf participants mean EQ-5D index value	0.804	0.902	0.559	0.897	0.793
95% CI	0.629 - 0.98	0.805 - 1	0.236 - 0.882	0.801 - 0.992	0.69 - 0.896
n	5	6	6	5	25
Health survey England mean EQ-5D index value	0.907	0.877	0.842	0.801	0.853
95% CI	0.895 - 0.920	0.858 - 0.895	0.820 - 0.865	0.788 - 0.813	0.845 - 0.861
n	663	478	512	1,468	3,121
Total					
Deaf participants mean EQ-5D index value	0.808	0.816	0.710	0.858	0.775
95% CI	0.715 - 0.902	0.688 - 0.945	0.602 - 0.819	0.787 - 0.928	0.724 - 0.826
n	18	15	26	14	89
Health survey England mean EQ-5D index value	0.893	0.863	0.829	0.786	0.838
95% CI	0.884 - 0.901	0.851 - 0.875	0.814 - 0.844	0.777 - 0.795	0.832 - 0.843
n	1,537	1,196	1,218	3,218	7,169
* Includes participants with missing age and gender.					

3.3 Assessment of which Deaf participant characteristics are associated with health status

The linear regression analysis found no evidence of an association between the participants' calculated EQ-5D index value and their captured demographic characteristics (Table 3, full model). Long standing physical illness, disability and the CORE-10 score were each associated with the EQ-5D index value, as expected. However, it is important to note that this analysis was limited to the 64 Deaf participants who had data on each of the variables. Using the 82 participants with incomplete demographic and health data, we ran a reduced form model that only included the health variables. A log-likelihood ratio test suggested that the reduced form model was nested in the full model (p=0.882). Accordingly, we ran the reduced model, which gave a slightly larger sample of 82/92 participants (Table 3, reduced form). This included an indicator for whether the participant was missing data on one or more demographic characteristics. The results indicate that the physical and mental health are associated with the EQ-5D index values, but also indicate that there are likely to be differences between participants with complete and incomplete demographic data.

Table 3 Relationship between EQ-5D index values and Deaf participants characteristics

EQ-5D index value	Coefficient	Standard Error	P=	95% Confidence Interval
Full model, n= 64/94 participants				
Age	0.001	0.002	0.670	-0.003; 0.004
Male (versus female)	-0.010	0.047	0.830	-0.104; 0.084
Not white British (versus white British)	0.030	0.053	0.571	-0.075; 0.135
Not productively active (versus productively active)	-0.039	0.062	0.531	-0.163; 0.085
Long standing physical illness (versus physically well)	-0.217	0.070	0.003	-0.357; -0.076
Disability (versus physically well)[a]	-0.341	0.077	<0.001	-0.495; -0.187
CORE-10 score, adjusted to take account of missing values	-0.009	0.004	0.043	-0.017; <0.001
Constant	0.921	0.095	<0.001	0.731; 1.111
Reduced model, n=82/92 participants				
Long standing physical illness (versus physically well)	-0.354	0.065	<0.001	-0.484; -0.224
Disability (versus physically well)	-0.346	0.084	<0.001	-0.512; -0.180
CORE-10 score, adjusted to take account of missing values	-0.012	0.004	0.005	-0.020; -0.004
Missing data on one or more demographic variables	-0.144	0.049	0.004	-0.241; -0.047
Constant	0.994	0.051	<0.001	0.893; 1.094

[a] Measured by asking participants: do you have a disability (yes/no)? Capturing whether the participant viewed themselves as having a disability.

Note: items excluded from the analysis (due to an overlap with other included variables, high level of missing data or difficulty collapsing responses) but captured in the survey included communication type, whether family members are Deaf, experiencing any health difficulties and education.

3.4 Comparison of health state values between people with and without psychological distress

Our third objective was to assess how EQ-5D index values vary between Deaf people with and without psychological distress or depression and how these compare to published figures for the wider population. For the anxiety/depression dimension of the EQ-5D over half (56%) of Deaf participants reported slight, moderate or severe problems. Although this is not a measure of prevalence it gives an indication that a substantial proportion of our participants were experiencing some psychological distress on the day of the survey. The CORE-10 cut-offs for psychological distress (CORE-10 score of 11 or more) and depression (CORE-10 score of 13 or more) were applied to the participant's data. These indicated that 58% of participants (95% CI 47%; 68%) had psychological distress and 43% (95% CI 33%; 54%) met the criteria for depression. In comparison, figures for the UK population suggest that overall 17% (95% CI 17%; 18%) of people in the UK aged 16 and over reported symptoms of anxiety or depression [28].

Table 4 summarises the index values of participants with and without psychological distress and depression and illustrate the impact of psychological distress or depression may have on the health status of Deaf people.

Table 4 EQ-5D index scores of Deaf participants with and without psychological distress and depression

Analysis	n/N	Mean Age (SD)	Female (%)	Mean index (SD) [95% CI]
Deaf BSL study participants				
All participants	86/92	45 (12)	70%	0.76 [0.71; 0.82]
Psychological distress (CORE-10 score of 11+)	49/85	45(12)	75%	0.69 [0.61; 0.77]
Depression (CORE-10 score of 13+)	36/85	44 (12)	74%	0.67 [0.58; 0.77]
No psychological distress/depression	36/85	45 (13)	69%	0.87 [0.61; 0.67]
No health problem [a]	31/85	46 (13)	68%	0.88 [0.84; 0.93]
Health Survey for England 2017, UK crosswalk system [19]				
All participants	7169/7997	N.R	56%	0.84 [0.83; 0.84]
Mental disorder	601/7165	N.R.	63%	0.62 [0.59; 0.64]
Long-lasting illness	2695/7165	N.R.	57%	0.75 [0.74; 0.76]
No long-lasting illness	3169/7165	N.R.	55%	0.92 [0.92; 0.93]
Mihalopoulos et al 2014 (Australia, UK, USA, Canada, Norway, Germany) UK crosswalk system [27]				
Participants with current depression diagnosis	917/8022	N.R.	66%	0.59 (0.25)
Mild depression/anxiety (K10 score 20-24)	152/917	N.R.	N.R.	0.70 (0.16)
Moderate depression/anxiety (K10 score 25-29)	172/917	N.R.	N.R.	0.66 (0.18)
Severe depression/anxiety (K10 score 30-50)	463/917	N.R.	N.R.	0.47 (0.27)
Healthy	1760/8022	N.R.	N.R.	0.88 (0.13)

[a] Participants described themselves as usually physically well and did not meet the threshold for psychological distress.
K10, Kessler Psychological Distress Scale; N.R. not reported; SD, standard deviation.

The decreases in health state values for our sample of Deaf people with psychological distress or depression appears to be similar to those found for the survey by Mihalopoulos et al (2014) [27]. The HSE data reports lower index values for adult participants with mental disorder [19]. However, this includes all mental health conditions, some of which may have more of an impact on health status than mild to moderate psychological distress or depression.

4. DISCUSSION

Our sample of Deaf BSL users in the UK reported more health difficulties across the EQ-5D dimensions, with lower associated index values (mean 0.78; 95% CI 0.72 – 0.83; n=89) when compared to a sample of the general population (mean 0.84; 95% CI 0.83 – 0.84; n=7,169). Participants demographic characteristics were not statistically significantly associated with health state values. However, presence of long-standing illness, disability and psychological distress were demonstrated to be statistically significantly associated with the index value as expected.

Overall, our findings are consistent with the literature; identifying reduced physical and mental health in the Deaf population, with an increase in the prevalence of mental health related conditions [5–8, 12]. The CORE-10 data demonstrated that psychological distress was commonly reported by our participants (58%) and 43% of the sample met the criteria for depression. This was higher than a previous estimate of the prevalence of depression in Deaf people (33%, n=431) [8]. These estimates suggest that psychological distress is more common in Deaf people than the general population in the UK. Data from the Understanding Society: the UK Household Longitudinal Study suggest that overall 17% (95% CI 17%; 18%) of people in the UK aged 16 and over reported symptoms of anxiety or depression [28]. The reduction in health state values, comparing people with psychological distress or depression to people without, for our sample of Deaf participants is similar to those found for the survey by Mihalopoulos et al (2014) [29]. This perhaps suggests that the impact of these conditions is similar in the Deaf population when compared with the general population.

4.1 Limitations

There are a number of limitations to the research. In particular, the limited sample size (n=92) makes it difficult to draw strong conclusions. The effect of this is most marked when looking at subgroups (e.g. by age group, and the population with and without depression). The small sample size limits the statistical power of the study to identify the impact of demographic characteristics such as age and gender on participants' health state values. The impact of this is especially noticeable in the older population group, for which the few responses received in the Deaf population reported very few problems on EQ-5D dimensions. Differences between the Deaf sample and wider general populations may be due to the age distribution in our sample of Deaf people. Due to the small sample size, simpler methods of analysis were preferred and applied; a larger sample would have enabled more exploration of the implications of the choice of methods (e.g. types of regression). In addition, it is possible that self-selection bias was introduced into the original translation and validation study due to the recruitment methods and advertising of the study, which in turn means our sample may not be reflective of the wider Deaf population [16]. Our sample include Deaf BSL users in the UK and may not be generalisable to Deaf communities in other countries.

When dividing the group with and without psychological distress, we applied the CORE-10 thresholds that are not specific to the Deaf BSL using population. Previous work conducted on other measures of health in the UK suggests that thresholds calculated for the general (assumed to be predominantly hearing) population may not be correct for the Deaf BSL population [29]. For example, PHQ-9 (a measure of depression) and GAD-7 (a measure of anxiety) has lower cut-offs for the Deaf population (8 and 6 respectively, compared to 10 and 8 respectively for the hearing population) [29]. If the assumption was made the CORE-10 cut-offs would be lower in the Deaf population, this would mean that our subgroup analysis is likely to be missing some Deaf participants with psychological distress. When considering further comparisons to the published studies, this would be confounded by the small sample of Deaf participants, as well as possible differences in the age and gender distribution between study. In addition, the use of different clinical measures to measure symptoms and different definitions of depression adds a further challenge; to measure psychological distress and depression in the Deaf population, the CORE-10 was used, whereas in the survey by Mihalopoulos et al (2014) the measure was the Kessler Psychological Distress Scale (K10). Furthermore, the HES data used ICD-10 codes for mental health diagnosis rather than a symptom checklist within the survey. Accordingly, it is hard to draw strong conclusions from these comparisons. Although anxiety and depression have different symptoms and people may have one or the other, it is most common for people to suffer from both with symptoms overlapping. Some treatment options work across anxiety and depression [30–33]. Additionally, measures used (such as the CORE-10 included in this paper) can capture symptom aspects of both. Therefore, we have focused on anxiety and depression more generally. It may be useful for future studies to consider the two independently as well as combined using a variety of measures.

Index values were calculated from the EQ-5D-5L BSL using the published crosswalk system [19]. The crosswalk system was estimated from EQ-5D health status data collected from a European sampled population and it is assumed that most of the population sampled would be hearing people. ‘Hearing’ in this sense might include people who were ‘deaf’ (e.g. through acquired hearing losses and older age) but is likely to exclude the population who are ‘Deaf’ and use BSL as their first or preferred language. Deaf people are recognised as having a distinct cultural-linguistic identity. This may mean that Deaf people have a different underlying valuation of health and ill health to hearing people [23, 34]. Therefore, investigation of how preferences for health vary in the Deaf BSL population would be interesting. Additionally, future populations investigating values for EQ-5D states, or population norms, should aim to include members of the Deaf population to ensure they are represented.

4.2 Implications for research

This is the first study to publish and explore health state values in the Deaf population. Overall, the current evidence base for the Deaf population is minimal and thus findings should be reassessed over time and as more specific evidence for BSL users becomes available. Nevertheless, the difference in health status suggests that research is needed to inform public health initiatives for BSL users to address and improve physical and mental health in the Deaf BSL population. A large prospective cohort study could overcome many of the limitations of the current study. By collecting more comprehensive demographic characteristics and clinical measures, health state valuation in the Deaf BSL population, including for a range of mental and physical health conditions, could be more fully investigated. This should include work to assess whether threshold values for commonly used mental health measures could be applied to the Deaf population.

There remain many more research questions pertaining to this group. For example, it would be interesting to conduct research that assesses whether being Deaf has the same health state impact on mental and physical health conditions. As access to services is likely to be highly variable, it would also be interesting to consider whether service availably is linked to health status and whether the provision of certain services in BSL can be

used to improve the health of the Deaf community. As noted within the literature, if Deaf people are excluded from shaping and designing healthcare, fulfilling patient-centred outcomes for Deaf people will not be attainable [35].

To date, Deaf BSL users have largely been excluded from clinical trials, likely due to fears that they would introduce confounding factors and English-language as an inclusion criteria [36–38]. Recent studies have increased the feasibility of including Deaf BSL users in trials, for example by exploring trial terminologies so the Deaf participants can make informed choices about participation, by translating common measures into BSL and by identifying relevant clinical cut-offs in this population [16, 29, 37]. Our findings demonstrate that results from hearing populations are unlikely to be generalisable to the Deaf population. Given the recent increase in tools that will enable Deaf BSL users to be more easily and robustly included in clinical trials, considering the Deaf population as a sub-group in trial analysis would be highly useful.

4.3 Conclusion

This is the first study to report and explore health state values from a sample of Deaf BSL users. According to our findings, Deaf BSL users more commonly report health difficulties on the EQ-5D dimensions and have lower index values, when compared with the general population. Psychological distress was reported by over half of participants, suggesting a greater prevalence of mental health problems in this population when compared with the general population in the UK. The difference in reported health status suggests that further research is needed to identify the reasons for this, and policy initiatives are required to address and improve physical and mental health in this population.

AUTHOR CONTRIBUTIONS

GES, KDR, LMD and AY planned the study. GES, LMD and KDR analysed the data. All authors contributed to the interpretation of the data. GES and SD conducted literature searching. GES and LMD drafted the first version of the manuscript and all authors contributed to subsequent versions. All authors read and approved the final manuscript.

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