An innovative and reliable way of measuring health-related quality of life and mental distress in the deaf community

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Original paper

Abstract Background Structured assessment of quality of life and mental distress in deaf people is difficult for various reasons. This paper describes the development and reliability of an interactive computer-based assessment package for measuring quality of life and psychological distress in the deaf population. Methods The Brief version of the WHO Quality of Life (WHO-QOL) Questionnaire, the 12-item General Health Questionnaire (GHQ-12) and the Brief Symptom Inventory (BSI) had been translated into sign-language and videotaped. A total of 236 members of the deaf community in Upper Austria participated by responding to a programme consisting of self-administered written and videotaped test-items presented to them on a notebook computer. The reliability of the various assessments was established on this large community sample. Results When reliability of the versions for the deaf was compared with that of written versions of the same measures in general population samples, it was found to be somewhat lower, although still in an acceptable range, for the WHO-QOL and the GHQ-12. For the BSI, the reliability was even higher than that of the general population. Conclusions For deaf individuals whose preferred communication is sign language, quality of life and mental distress can be effectively and reliably assessed with the use of carefully translated and adapted common instruments.

Key words quality of life – deaf – interactive video – screening questionnaires – mental health

Introduction

In social and medical health care, reliable assessment of quality of life and mental health are of increasing importance in the development of services and for the distribution of resources. For this reason, a larger study has been undertaken on quality of life and mental health in the deaf population of Upper Austria. The methodology and the results of this large study will be described later. One major problem was the adaptation of research instruments for the deaf population.

Usually, assessment is based on the use of written questionnaires which exclude individuals whose reading ability is absent or poor. As the average reading level of prelingually deaf people (prevalence rate 0.1%) (Schein 1979) is far below that of the general population, paper-pencil tests are not appropriate. Gelter (1987) demonstrated that only 10% of deaf school-leavers in Austria achieve a level of reading comprehension of pupils who finish primary school. This reading level is necessary to understand simple texts as presented in a daily newspaper. International data on reading of the deaf show similar results (Holt 1994). These low reading levels do not interfere automatically with capacity to understand more differentiated terms of psychological tests if they are presented in sign language. The deaf community is characterised by the use of sign language and by intensive socio-cultural cohesion which can make access for hearing researchers difficult. In practice, the use of interpreters brings about a high risk of bi-
ased results. Therefore, self-administration was the preferred option, especially as the quality of life questionnaire had to be combined with measures of mental distress in order to get information about specific mental health needs of the deaf.

Lipton et al. (1996) and Steinberg (1998) describe the development of interactive video questionnaires with the deaf. However, they did not report reliability data based on large community samples with a high diversity of competence in signed and written language.

The aim of the present part of the study was to produce a version of accepted research instruments dealing with quality of life and mental distress that can be applied to the general population of deaf people, including those with late access to sign language and little language development.

**Subjects and methods**

### Measures

The Brief version of the World Health Organisation’s Quality of Life Questionnaire (WHO-QOL) (WHO Group 1998; Angermeyer et al. 2000) and the 12-item General Health Questionnaire (GHQ-12) (Goldberg and Williams 1988; Üstün et al. 1995; German translation Linden et al. 1996) are both relatively short measures intended for international use with established normative data. The Brief Symptom Inventory (BSI) (Derogatis et al. 1982; Franke et al. 2000) is derived from the SCL-90 and provides scales for specific symptoms. To keep the assessment battery acceptable in length and to avoid rejection due to questions for “strange symptoms” (e.g. psychoticism), for the purposes of the present study only five symptom scales were selected, dealing with more common problems like anxiety, somatisation, depression, paranoid ideation and interpersonal sensitivity. In all instruments standardised German versions were used.

The WHO-QOL was chosen to measure quality of life in deaf people. The GHQ was mainly used for assessing the prevalence of psychiatric disorder in this population. The BSI was used for assessment of severity of selected psychopathology.

### Preliminary work for the videotaped materials

Contact was established with ten leaders of deaf clubs in Upper Austria and the purpose of the research was described to them in detail. Many of them were able to read the written materials, these were also explained to them in sign language. The leaders were asked how to express each item on the WHO-QOL, the GHQ and the BSI in their own local sign language.

The group of leaders then reconvened and compared their various suggestions together with three experts – a psychiatrist (first author), a linguist (second author), and an interpreter. The group selected the best version of each item.

Two leaders – one male, the other female – were asked to demonstrate the test material on videotape. When this had been done, three independent sign language interpreters who had not participated in the preliminary work back-translated this material into written German, and these back-translations were checked by the linguist. Agreement between the back-translated and the original versions occurred in 98% of the cases. Disagreements were resolved by the original deaf group, who were asked to suggest a new version of the disputed item in sign.

The chosen versions of each item were incorporated in a multimedia computer program for self-administered interviews that required 135 megabytes of memory on each laptop computer. A special user interface was designed according to the needs of the deaf (see Fig. 1).

Each item appeared on the screen in written German and was reproduced in sign language by one of the two demonstrators. After each item, the demonstrator presented the possible response categories. The demonstrator would smile for “very good” while indicating “very good” in sign; there would be a negative appearance for “very poor”. For two items where “not at all” indicated health (i.e. “How much do you need medical treatment to function in your daily life?”), the demonstrator would smile for “not at all” and look concerned for “an extreme amount”. The answer categories of the BSI could be translated easily by signs showing different degrees of severity of the symptomatology.

The button corresponding in colour to each possible reply ap-

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**Fig. 1** WHO-QOL Bref

![WHO-QOL Bref Screenshot](image_url)