Quality of Life, family function and mental health of deaf and hard-of-hearing adolescents in mental health services in Norway – a pilot study

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ABSTRACT
Object: The main aim of this study was to gain a better understanding of Quality of Life, family functioning and mental health for Norwegian deaf and hard-of-hearing children and adolescents. Method: We used the Inventory of Life Quality for Children (ILC), McMaster Family Assessment Device (GFS) and the Strengths and Difficulties Questionnaire (SDQ). These instruments were used to assess Quality of Life, family functioning, emotional and behavioural problems in deaf and hard-of-hearing (n= 20) and hearing Child and Adolescent Psychiatry (CAP) patients (n = 717) as well as in a hearing normative sample (n= 1032). Results: We found that Quality of Life and family functioning of deaf and hard-of-hearing (DHH) CAP patients were comparable to those of their hearing CAP peers. DHH CAP patients showed a non-significant tendency to report more emotional and behavioural difficulties than hearing CAP patients. Conclusion: Based on these results, Norwegian deaf and hard-of-hearing CAP patients score similarly to their hearing peers in CAP on measures of Quality of Life and family function, whereas there may be a tendency for DHH CAP patients to report more emotional and behavioural problems than hearing CAP patients. Due to the very small sample size more research is needed on the subject.

KEYWORDS
Deaf, hard-of-hearing, adolescents, Quality of Life, family function, mental health

Introduction

Quality of Life and Deafness

Quality of Life (QoL) is a subjective concept based on self-report and is associated with better physical and mental health as well as providing information on other important aspects. It is therefore important to assess Quality of Life in health studies1.
Children with posttraumatic stress disorder, depression and alcohol abuse\(^2\) and adolescents with attention deficit disorder\(^3\) have been found to have lower QoL than healthy controls. Jozefiak et al.\(^4\) showed that children and adolescents referred to Child and Adolescent Psychiatry (CAP) had lower QoL than children from a normative sample when matched for emotional and behavioural problems in both samples. Quality of Life has been emphasised as an important measure to complete assessment of psychiatric symptoms\(^4\). Jozefiak, Larsson and Wichstrom\(^5\) showed a decrease in QoL with age, especially for girls during puberty.

Quality of Life for deaf adults has been reported to be the same as for hearing adults, whereas hard-of-hearing adults have reported lower QoL\(^6\)\(^-\)\(^8\). Cochlear Implants seem to improve QoL in postlingually deaf adults\(^9\). For 4 to 7-year-old children with cochlear implants normal levels of QoL have been reported, with lower levels reported in older children\(^10\)\(^-\)\(^11\).

Fellinger et al.\(^12\) found that parents of deaf and hard-of-hearing (DHH) children rated their children’s QoL similar to that of parents of hearing children, with significantly higher scores indicating better QoL on the following subscales: family functioning, interests and recreational activities and physical health. The DHH children rated themselves higher than their hearing peers on the subscales school and family, and lower on interests and recreational activities and physical health. Hintermair\(^13\) found the Inventory of Life Quality (ILC) to be a valid screening tool of QoL in DHH children, and in a later study found the QoL of mainstreamed DHH students to be comparable to that of a normative hearing sample\(^14\). Schick and Skalicky\(^15\) found that school placement did not influence QoL. In the same study Schick and Skalicky\(^15\) found that DHH students with deaf parents had more positive QoL scores, with more participation and less stigma than DHH students with hearing parents.

There are to the authors’ knowledge hardly any studies of family functioning in families with deaf and hard of hearing children. Fisiloglu and Fisiloglu\(^16\) compared parent reports of family functioning in families with deaf and hard of hearing children to reports of family functioning in families with hearing children and reported no differences between the two groups. The authors argued that families with deaf and hard of hearing children adjust well to the stressors of having a child with hearing loss.

Watson and Henggeler\(^17\) examined the associations between family functioning and the social adjustment of DHH adolescents. They found DHH adolescents’ behavioural problems to be closely related to parental symptomatology and low family adaptability. In addition, they found that the social competence of DHH adolescents was closely related to family stress.

Mental health and deafness

Previous studies have shown that 45 to 49% of deaf children and adolescents have mental health problems\(^18\)\(^-\)\(^20\). Factors such as age at time of hearing loss, degree of hearing loss, the child and family’s communication skills, cognitive function, type of schooling, as well as visual and motor impairment and neurological difficulties have been shown to be both risk and protective factors in children and adolescents\(^20\)\(^-\)\(^21\). Factors such as communication problems, low self-esteem as well as problems accepting hearing loss have been shown to play an important role for mental health problems in adults\(^22\). Van Gent and Goedhart\(^21\) reported self-esteem and peer rejection to be associated with emotional health problems in deaf adolescents, with degree of hearing loss acting as a moderating factor. In addition, they found a negative association between behavioural difficulties, social acceptance and peer acceptance. Comparing the characteristics of deaf children and adolescents in in- and outpatient mental health services to hearing children, Van Gent and Goedhart\(^23\) found higher rates of environmental
stress (more one parent families), parents with a low educational level, increased age at first referral, and a higher rate of pervasive developmental disorders and mental retardation for deaf children.

At present, there is a lack of knowledge on deafness and mental health. Some of the existing studies are methodically weak as they do not mention participants' communication skills or favoured mode of communication, communication used in the studies or the researchers knowledge of sign language\textsuperscript{24, 25}. Studies that compare written assessment to assessment based on sign language have shown more reported symptoms of mental health problems for assessment in sign language\textsuperscript{26}. Studies rarely use standardised assessment tools in sign language or share information on translation procedures. Furthermore, samples in these studies are rarely representative and information about the participants’ demography including ethnicity, type and grade of hearing loss, which have been shown to have an effect on mental health in the deaf and hard-of-hearing, are missing. As stated by Connolly, Rose\textsuperscript{25}, “given the current limited evidence base, there is a pressing need for clinically useful research in the area of deafness and mental health” (p. 59).

Fellinger & Holzinger\textsuperscript{6}, De Graaf & Bijl\textsuperscript{22}, Black & Glickman\textsuperscript{24} and Dammeyer\textsuperscript{27} all found that the level of communication skills has an impact on mental health problems. Other studies have shown that deaf and hard-of-hearing children and adolescents with good communication skills (signed and/or spoken) do not show a higher rate of mental health problems than hearing peers\textsuperscript{28}. Norwegian research on mental health and deafness is scarce and focuses on deaf adults\textsuperscript{29,31}. There are at present no studies on Norwegian deaf adolescents and mental health, Quality of Life and family function. As Norway is unique in offering parents of deaf and hard-of-hearing children 40 weeks of sign language classes over 16 years with all expenses covered one might expect a higher level of signing skills amongst Norwegian deaf and hard-of-hearing children and adolescents. This in turn may have a positive influence on their mental health.

**Aims**

The main aim of this pilot study was to gain a better understanding of QoL, family functioning and mental health for deaf and hard-of-hearing children and adolescents. We achieved this by comparing deaf and hard-of-hearing children and adolescents who were referred to CAP with their referred hearing peers as well as with non-referred hearing peers using norms on standardised assessment tools.

**Method**

**Participants**

*The CAP sample*

The CAP sample in this study was part of The Health Survey in the Department of Child and Adolescent Psychiatry (CAP Survey) in the University hospital of Trondheim in central Norway. This was a cross-sectional study based on a clinical sample. Referred adolescents, aged 13 to 18 years, who had at least one personal attendance at the clinic between 2009 and 2011, were included in the study. Exclusion criteria were major difficulties in answering the questionnaire due to their psychiatric state, cognitive function, visual impairments or lack of sufficient language skills. 717 patients (mean age 15.66) participated in the survey (393 girls and 324 boys). For more detailed information about the CAP Survey, see Ranoyen et al\textsuperscript{32} and Schei et al\textsuperscript{33}.

*The deaf and hard-of-hearing sample*

The deaf and hard-of-hearing sample is based on the same CAP Survey. Twelve of the 717 subjects included were deaf or hard-of-hearing and participated in the present study. To increase the number of participants all deaf and hard-of-hearing adolescents from the regional deaf CAP, in the same region were invited to participate between 2012 and 2014. The same exclusion criteria were used for
the supplementary participants as in the CAP-Survey. All eight patients who were invited agreed to participate which resulted in a total of 20 participants for the present study. The characteristics of this sample are presented in Table 1.

Table 1. Sociodemographic, hearing and language-related characteristics of the participating adolescents and their families.

<table>
<thead>
<tr>
<th></th>
<th>N</th>
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<tr>
<td>Gender</td>
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</tr>
<tr>
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</tr>
<tr>
<td>Boys</td>
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<td>25</td>
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<td>60</td>
</tr>
<tr>
<td>16 to 19 years</td>
<td>8</td>
<td>40</td>
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<tr>
<td>¹DHH family member(s)</td>
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<td></td>
</tr>
<tr>
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<td>5</td>
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<td>10</td>
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<td>20</td>
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<tr>
<td>Severe: 71-100 dB</td>
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</tr>
<tr>
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</tr>
</tbody>
</table>

¹DHH: Deaf and hard-of hearing

The general population reference sample.

For comparison, we had access to data from a study sample of students from 4th to 10th grade from schools in Sør-Trøndelag county, which represents a comparable geographical area with both urban and rural settlement. In this study, 61 school grade cohorts in the chosen geographical area were randomly selected. Students with limited Norwegian language skills or with a low academic developmental level were excluded. Students in 4th, 6th, 8th and 10th grade were invited to the study. 1997 students were finally included (990 girls and 1007 boys), resulting in a response rate of 71.2%. Of these 492 were from 8th grade (12-14 years old) and 538 from 10th grade (14-16 years old). Students from 4th and 6th grade were not used as a comparison for this study as they were too young compared to the DHH adolescents in this pilot study.

Students and their parents completed the Inventory of Life Quality (ILC) and the Norwegian version of the General Functioning Scale of the McMaster Family Assessment Device (GFS) independently. For further details, see Jozefiak, Larsson34.

Measures

Sociodemographic, hearing and language-related information.

Parents and adolescents completed a demographic form with information about age, sex and SES, all part of the original CAP study. In addition, the same measures were used in the present pilot study as in the CAP Survey unless otherwise specified. Parents and adolescents in the present pilot study also completed a questionnaire specially designed for assessing type and severity of
hearing loss, sign language skills, type of schooling, and parents’ attendance of sign language classes.

**Quality of Life**

QoL was measured using the Norwegian version of the Inventory of Life Quality in Children and Adolescents - ILC34-36. The seven-item parent proxy and self-report include one item for overall QoL and six items addressing the child’s physical and mental health, school and family functioning, social contact with peers, interests and recreational activities. Items are rated on a 5-point scale from “very good” to “very bad”. The QoL Score (LQ28) is computed using a scoring algorithm based on these seven items with a possible range of 0-28. Lower LQ28 total score reflecting a poorer overall Quality of Life. The Norwegian self and parent-report (36) has satisfactory reliability for children and adolescents above 11 years old (self-report: Cronbach’s α = 0.80 to 0.82, parent-report: Cronbach’s α = 0.78).

**Family functioning**

Family functioning was measured using the Norwegian version of the General Functioning Scale of the McMaster Family Assessment Device - GFS. The 12-item parent proxy and self-report of the GFS measure family functioning based on six different areas, including problem solving, communication, roles, affective responsiveness, affective involvement and behavioural control. Each item was rated on an ordinal scale (1 = strongly agree, 4 = strongly disagree). The total score is based on the sum of these (range = 12-48), higher scores indicating poorer functioning. A cut-off point at ≥ 24 is used to determine if adolescents are affected by unhealthy family functioning. The reliability of the GFS is good, with a Cronbach’s alpha of 0.9238. The construct validity of the GFS was supported by findings in the Ontario Child Health study, a large epidemiological study of children aged 4 to 16 years. In Norwegian studies the GFS differentiated meaningfully between subgroups and showed a satisfactory fit to the data in confirmatory factor analysis.

**Emotional and behavioural problems**

The Strengths and Difficulties Questionnaire – SDQ is a multi-informant mental health questionnaire that can be used as a screening tool. The SDQ can be used for children and adolescents, and is completed by either a parent, teacher or an adolescent (self-report). Each version of the questionnaire comprises twenty-five questions, each scored on a three point Likert scale. These questions can be divided into five subscales measuring emotional problems, conduct problems; hyperactivity-inattention, peer problems and prosocial behaviour, as well as a total difficulties scale of overall psychological adjustment based on the four negative subscales, higher scores indicating more difficulties. The SDQ has a satisfactory internal consistency (Cronbach alpha ranging from 0.80 to 0.87) and specificity and sensitivity ranging from 94-95% and 23-47%, respectively, for the different versions of the SDQ.

Hintermair examined the usability of the German parent-report version of the Strengths and Difficulties Questionnaire (SDQ) for assessing emotional and behavioural problems in deaf and hard-of-hearing children and found it satisfactory. Cornes and Brown established the usefulness of the written and signed Australian version of the SDQ for deaf and hard-of-hearing adolescents.

**Procedures**

The deaf and hard-of-hearing sample

In the CAP Survey referred patients and patients already enrolled at the CAP received oral and written information about participating in the study at their first attendance after the survey was initiated. Written informed consent was obtained from adolescents and parents prior to inclusion, according to the CAP survey procedures. The participating adolescents responded to a web-based questionnaire at the unit and data were collected from
clinical records. Parents also responded to a questionnaire on socioeconomic status, including educational level of both parents. Deaf adolescents had access to a sign-language interpreter and/or a psychologist fluent in sign language.

In the supplementary data collection for the present pilot study referred patients and patients already enrolled at the regional deaf CAP received oral and written information about participating in the pilot at their first attendance after the survey was initiated. Written informed consent was obtained from adolescents and parents prior to inclusion, according to the procedures of the pilot study. The participating adolescents and parents responded to a paper and pencil questionnaire version based on selected instruments from the CAP Survey. Supplementary data were collected from clinical records. All deaf and hard-of-hearing adolescents and their parents also completed a sociodemographic and hearing related questionnaire. Parents of signing adolescents were asked to rate their children’s signing skills.

The general population reference sample.

One teacher at each school was appointed as a project coordinator. The coordinator informed the students about the project and sent a standard information letter to their parents. The research assistant was present at each school when the students completed the questionnaires at each assessment occasion. Completed questionnaires marked with an ID number only were collected in sealed envelopes by the researchers.

Parents and adolescents from both samples completed the assessments described in the paragraph on measures.

Statistics

According to ILC scoring guidelines for individuals with 1 to 3 items missing, data were substituted. In the present study, we used Expectation Maximization (EM) algorithm procedures. Equivalent procedures were performed for the GFS scale and the SDQ.

Differences between group means for DHH and hearing CAP patients as well as a hearing normative sample on ILC and GFS and SDQ were examined by analysis of covariance (ANCOVA), adjusting for age and gender. Differences between group means for DHH and hearing CAP patients on SDQ were examined by analysis of covariance (ANCOVA), adjusting for age and gender. A level of < .05 was chosen to indicate statistical significance. Assumptions for the ANCOVA were checked. Levene’s Test was found significant for ILC and GFS indicating that the assumption of homogeneity of variances has been violated for this dataset. This is likely due to the extremely small sample size of the DHH CAP sample. To adjust for different n in the groups (normal population, DHH CAP and hearing CAP) we used “Type I” for the sum of squares in the grouping variables. Levene’s Test for SDQ was found not to be significant indicating that variances in the two different groups were equal. The association between mental health and QoL for both DHH and hearing patients were analysed using linear regression analysis. Shapiro-Wilk tests showed that the scores for self-reported QoL (W = .922, p = .374), self-reported family function (W = .948, p = .642), parent-reported family function (W = .973, p = .919), self-reported SDQ (W = .970, p = .803) and SPAI-C (W = .929, p = .185) for the DHH sample had a normal distribution.

Ethics

Written informed consent was obtained from adolescents and parents prior to inclusion, according to the study procedures in the CAP survey and the supplementary study at regional deaf CAP. Study approval was given by the Regional Committees for Medical and Health Research Ethics (reference numbers CAP survey: 4.2008.1393, present study: 2013/1226).

Results

Quality of Life
The analysis of covariance (ANCOVA) revealed an effect of age (F1, 1739) = 56.719 p < .001, η^2_p = .032 and gender (F1, 1739) = 80.355 p < .001, η^2_p = .044 on the adolescents’ self-reported QoL. Age and gender explained a significant proportion of variance in QoL scores, R^2 = .248, p < .001. Age (b = -.598, SE = .079, p < .001) and gender (b = 1.865, SE = .208, p < .001) had a significant effect on self-reported QoL scores, indicating that the older adolescents and girls reported lower QoL. This effect was not found for the adolescents’ parent-reported QoL. The ANCOVA also showed a significant effect of group on self-reported QoL (F2, 1739) = 87.432, p < .001, η^2_p = .091 and parent-reported QoL (F2, 1397) = 272.302, p < .001, η^2_p = .280.

**Family function**

The ANCOVA revealed an effect of age (F1, 1722) = 22.721, p < .001, η^2_p = .013 and gender (F1, 1722) = 10.555 p < .001, η^2_p = .006 on self-reported family function (GFS). Age and gender explained a significant proportion of variance in scores on family function, R^2 = .107, p < .001. Age (b = -1.014, SE = .312, p = .001) and gender (b = .565, SE = .119, p < .001) had a significant effect on self-reported family function scores, indicating that the older adolescents and girls reported lower family function. Further an effect of age (F1, 1397) = 5.615, p = .018, η^2_p = .004 on parent-reported family function was found. The ANCOVA also showed a significant effect of group on self-reported (F2, 1722) = 5.615, p < .001, η^2_p = .041 and parent-reported family function (F2, 1397) = 6.523 p = .002, η^2_p = .009.

Post-hoc analyses showed that deaf and hard-of-hearing (DHH) patients’ scores on Quality of Life (ILC) and family function (GFS) did not differ significantly from those of hearing patients (self and parent report). However, CAP patients (DHH and normal hearing) scores on Quality of Life and family function were significantly lower compared to their peers in the community sample (self and parent report). CAP patients (DHH and normal hearing) also scored above the cut-off on FAD-GFS (self-report only) indicating low family function (Table 2).

Table 2. Comparison of QoL (ILC) and family function (GFS) scores based on self (SelfQ) and parent (ParQ) report for DHH and hearing patients and general population sample.

<table>
<thead>
<tr>
<th></th>
<th>DHH CAP (SelfQ N=18; ParQ N=11)</th>
<th>CAP (SelfQ N=694; ParQ N=506)</th>
<th>GP^1 (SelfQ ParQ N=1032)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M (SD)</td>
<td>Sign.</td>
<td>M (SD)</td>
</tr>
<tr>
<td>ILC LQ SelfQ</td>
<td>17.44 (6.35)</td>
<td>0.003</td>
<td>17.93 (5.14)</td>
</tr>
<tr>
<td>ILC LQ ParQ</td>
<td>19.09 (2.91)</td>
<td>0.000</td>
<td>18.45 (4.56)</td>
</tr>
<tr>
<td>GFS TS SelfQ</td>
<td>25.73 (8.16)</td>
<td>0.058</td>
<td>25.53 (7.24)</td>
</tr>
<tr>
<td>GFS TS ParQ</td>
<td>23.45 (6.86)</td>
<td>0.051</td>
<td>21.67 (5.37)</td>
</tr>
</tbody>
</table>

^1GP: General population reference sample
^2Low family functioning based on cut-off 24 for GFS

**Mental health**

The ANCOVA for DHH and hearing CAP patients revealed an effect of gender (F1, 418) = 29.94 p < .001, η^2_p = .067 on the adolescents’ self-reported mental health (SDQ total score). Gender (b = -3.020, SE = .552, p < .001) had a significant effect on self-reported SDQ total scores, indicating more mental health problems for girls. The ANCOVA also showed a tendency for effect of group on self-reported mental health (F1, 418) = 3.70, p = .055, η^2_p =.009, DHH CAP patients reporting lower scores than their hearing peers in CAP.

**Discussion**

The present study found that QoL and family function of DHH CAP patients are comparable to those of their hearing CAP peers. We found that self-reported QoL
decreased with increasing age for all groups. Lower QoL for older adolescents and girls as found in this study are in accordance with Jozefiak, Larsson results. Due to the small sample size of the DHH CAP sample it was not possible to analyse if this age effect is greater for the DHH CAP patients than for the other two groups.

QoL in DHH has previously been shown to be the same for deaf adults and young children as for hearing adults and children. Studies assessing QoL with the ILC have confirmed the validity of the instrument for DHH adolescents and found comparable QoL to that of hearing peers. Our finding that DHH CAP adolescents have the same QoL as hearing CAP patients is therefore in accordance with these previous studies.

As for family function, Fisiloglu and Fisiloglu report no differences in the functioning of DHH families compared to hearing families when assessed using the GFS. Our findings in this study may be seen as in accordance with their findings, although we do not know of studies comparing QoL and family function in DHH children and adolescents in CAP with those of hearing CAP patients.

The SDQ has previously been reported to be a valid tool for assessing DHH children’s mental health in Australia and Germany. When comparing DHH CAP with hearing CAP patients the present study found that DHH CAP patients tend to report more emotional and behavioural difficulties than hearing CAP patients. This observed difference was only borderline significant at the p=0.055 level, probably due to the small sample size. One might reason that this observed difference may be due to later referral to CAP units than for their hearing peers as symptoms of mental health problems may be attributed to hearing loss and communication difficulties, resulting in a greater number of symptoms by the time of referral. An alternative explanation might be the increased risk of mental health problems found in DHH children and adolescents.

As the results in the present study are based on a small sample size it was not possible to assess differences for the DHH CAP patients according to their severity and aetiology of hearing loss, preferred mode of communication and type of schooling. All these factors have previously been shown to affect mental health in DHH.

The parents’ response rate to the questionnaire assessing their adolescents signing skills was too low for this information to be included in the present study. As previous studies have shown the importance of communication skills for mental health problems the lack of this information may mask individual differences in this sample.

Limitations

The results of this study are based on a very small sample of deaf and hard-of-hearing patients. The study also lacks data of a deaf and hard-of-hearing control group not admitted to CAP. Therefore, these findings cannot be generalised to the deaf and hard-of-hearing in the general population. Furthermore, the assessment was carried out using written assessment tools which have previously been shown to under-report symptoms of mental health problems.

Conclusion

In this pilot study we found that deaf and hard-of-hearing CAP patients are similar to their hearing peers in CAP on measures of Quality of Life and family function. There may be a tendency for DHH CAP patients to report more emotional and behavioural problems than hearing CAP patients. Deaf and hard-of-hearing CAP patients differ significantly from community samples (hearing) on the same measures. These results, however, cannot be generalised to the general deaf and hard-of-hearing population due to the limitations of the study.

Further research on deaf and hard-of-hearing children and adolescents’ mental health is needed, especially on the
deaf and hard-of-hearing community population in Norway.

Acknowledgments

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Conflict of interest

On behalf of all the authors, the corresponding author states that there is no conflict of interest.

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