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Specialized outpatient clinic for deaf and hard-of-hearing patients in the Netherlands: Lessons learned in an attempt to improve health care

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Abstract

Rationale, aims, and objective: A group of organizations and individuals in the Netherlands collaborated to attempt to improve access to health care and health education for deaf and hard of hearing (DHH) patients in the country. The outcome was the start of a specialized outpatient clinic named PoliDOSH. An independent research group was set up to evaluate the effect of this specialized clinic. Even though the initiative did not succeed and was closed after 2 years, an extensive analysis of the start-up and functioning of the whole process was made.

Methods: Structured and nonstructured questionnaires and structured interviews.

Results: Only a small group of DHH patients indicated that they felt a need for consultations at the PoliDOSH. It became clear that to ensure successful functioning of a specialized facility the team members should include a representative group of DHH members. All key functions should be filled by top experts in the relevant fields as well as an expert in communication and needs of the target group.

Conclusions: There is a great need for facilities to collect and disseminate information to and about DHH patients. The information should be aimed at providing psycho-education for the DHH persons themselves and health care professionals, concerning the specific needs and problems of this patient group. If a similar facility is set up in the future, thorough market research prior to start up is needed to enable the facility to connect with the needs of patients. The start-up period should allow sufficient time for the project to become known and for patients to become familiar with it and trust it.

KEYWORDS

deaf, hard of hearing, health services research, health care access, health care evaluation, public health

1 | INTRODUCTION

Deaf and hard of hearing (DHH) patients' access to health care facilities is difficult for several reasons.¹⁻¹⁷ Communication is the greatest

barrier, as availability and use of sign language (SL) or speech-to-text mediation by interpreters is restricted and medical information in SL is often scarce.^{5,9} DHH patients often have less knowledge about health and health care subjects.^{8,12,18-23} Low literacy and cultural

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features are also a factor.^{22,24,25} Access of DHH patients to health care is a worldwide problem, and only a few centers have paid specific attention to this. In the Netherlands, there are no specialized general health facilities for this group. A group of individuals in the Netherlands attempted to improve access to health care and health education for DHH patients by starting a specialized outpatient clinic for deaf and hard-of-hearing patients (acronym PoliDOSH). The organization of PoliDOSH mirrored that of specialized outpatient clinics for DHH patients in Austria.¹

An external independent group (including the authors of this paper) was asked to evaluate the effect of this clinic. The findings are reported in this paper, and advice is given concerning setting up a similar facility in the future in the Netherlands or elsewhere.

2 | METHODS

The project was planned for a minimum of 3 years. However, after 1.5 years, it became clear that the outpatients' clinic did not attract a sufficient number of patients to evaluate this initiative according to the analysis plan. An alternative quantitative analysis plan was written and executed. Data were collected in three different manners:

- A questionnaire among PoliDOSH patients (2.1)
- Structured interviews (2.2)
- A questionnaire among members of the Deaf community (2.3).

2.1 | Questionnaire completed by PoliDOSH patients

This questionnaire included questions on the referral process, communication, the content of the consultation, the patients' general experience with the PoliDOSH, and epidemiological questions. The results were returned directly to the investigator allowing these to be analysed anonymously.

2.2 | Structured interviews with PoliDOSH personnel and representatives of interest groups

Ten structured interviews were carried out concerning the start of the PoliDOSH and how it functioned. Eight of these were with personnel of the PoliDOSH and members of the project group. They consisted of one physician (hearing), one nurse (suddenly deafened), one NGT interpreter (hearing), two secretaries (one deaf and one hearing), one project leader (hearing), and two advisors (both deaf, one of whom was previously a board member of Dovenschap²). Three structured interviews were carried out with people who represent interest groups, one sitting board member of Dovenschap²(deaf), one ex-board member of Dovenschap (deaf with a double role as this person was also an advisor for PoliDOSH), and one member of the mill organization³ (hearing). The questions concerned how they experienced the setup and organization

of PoliDOSH, strengths and difficulties, how they estimated the need for PoliDOSH, and suggestions for improvement.

2.3 | Questionnaire: Deaf community

Based on information from the structured interviews (2.2) and anecdotal information gained from conversations with visitors of the Amsterdam Foundation for the Wellbeing of the Deaf (AKA the Deafclub in Amsterdam), a short questionnaire was developed in both NGT and written Dutch. This contained ten questions concerning awareness of the PoliDOSH and the need for specialized health care. It was distributed by 14 clubs and organizations for Deaf people in the Netherlands, support organizations, Facebook pages of a Deaf Gain meeting group, and the investigators.

The questionnaires were completed online using Unipark software²⁶ and can be obtained from the corresponding author. The questions were presented in NGT and in written Dutch.

3 | RESULTS

The results will be discussed per dataset.

3.1 | Questionnaire completed by PoliDOSH patients

During the 19 months of operation, 23 patients have attended this facility. No negative answers were given, and no patients offered suggestions for improvement. Statistical analysis or comparative evaluations were not possible in view of the very small number of respondents

3.2 | Results of structured interviews

The original initiative for setting up the PoliDOSH was taken by staff members of Royal Dutch Kentalis.²⁷ This is a national organization providing diagnostic, educational, and care services for DHH people. At the start of PoliDOSH, there was resistance to this because people were apprehensive about the possibility that their medical information could be made available to nonmedical departments within Kentalis.

According to the original staff members of PoliDOSH, they had underestimated the complexity and enormity of this project. The 3-year duration of the project was too short to get such a facility up and running. Reasons given were that a process of consciousness arousal of DHH people is necessary to allow them to become aware of their own higher risk of health problems and that deep-seated mistrust of some DHH patients towards the medical and paramedical professions means that it will take time to win their trust. Looking back, representatives of the support groups should have been involved at an earlier stage.

Medical care in the Netherlands is organized so that almost everyone has one or more general practitioner (GP) practices within

walking distance and a hospital within a radius of 5 km of their home.²⁸ Several participants indicated that they considered the travel time to the PoliDOSH too long. Their views about an acceptable journey time ranged widely. All PoliDOSH personnel members indicated that they would not personally seek medical care at a facility like PoliDOSH, or only as a second opinion after they had attended several other physicians without their problems being resolved.

Three interviewees indicated that it would be better if there were more DHH team members, creating a better representation of the different target groups in the team. All eight personnel members mentioned the cooperation within the team, the team spirit, trust in each other, and how they had loved working together in the end. But this had not been the case from the beginning. Hearing members had to get used to the working style of deaf members, learn to listen to the deaf members, and first to gain the trust of the deaf members. The target group consists of very diverse subgroups, depending on hearing status, background, and age. The team gradually became more acquainted with the specific (deaf cultural) aspects of the target group, which led to better communication and information.

According to the personnel, the success of the project is that some medical information is now available in NGT, and a general practice-based nurse specialist especially for DHH patients has been appointed at a general practice in the vicinity of the only center in the Netherlands for elderly deaf people. On one occasion, PoliDOSH organized a "health fair" for DHH persons with presentations, an information market, and discussions about various health subjects.²⁹ Many respondents indicated that they found the information meetings, and this health fair very useful.

3.3 | Evaluation of the online questionnaire among the deaf community

The group of patients that PoliDOSH did actually reach was people who are deaf from the prelingual period. Therefore, the questionnaire to evaluate functioning of PoliDOSH was specifically aimed at this target group. Thirty-six respondents completed the questionnaire. Five non-DHH participants were excluded. Twenty-two respondents stated that they were aware of the presence of PoliDOSH, and three had visited it. These three patients had been satisfied with the care they received.

Two-thirds of the respondents stated that they would certainly, or possibly, attend PoliDOSH should they have physical complaints in the future. One-third of the respondents indicated that they would certainly not attend the PoliDOSH. The reason most often given for this was the long distance or travel time. Four respondents gave various reasons why they (as yet) did not trust the PoliDOSH.

4 | DISCUSSION

There seems to be a discrepancy between the original plan and the actual needs of DHH people in the Netherlands. Almost all

participants indicated that DHH people will attend specialized care only if the regular medical health care system did not succeed in solving their problems. Therefore, it could have been expected that the number of patients who would attend the PoliDOSH would remain limited.

A possible intervention to balance the need for proximity of care vs expertise in the Netherlands is to strengthen the network of health care providers with DHH expertise, in combination with a national specialized center which could play an important role in centralizing care, providing information and supporting second opinion consultations.

The number of DHH medical professionals is limited; to deliver high standard care, you will need a team of DHH and hearing professionals working together. Young et al.³⁰ have stated that teams of service providers comprising deaf and hearing members face enormous challenges in developing effective working relations. These dynamics were also seen within the PoliDOSH team and should be anticipated in these types of teams in future.

4.1 | Recommendations

- Investigate the specific needs of DHH subgroups in your region prior to setup.
- It is essential that projects are supported by the target group itself and that the target group is fully represented in the team.
- The start-up period should be sufficient to allow time for the project to become known and for patients to become familiar with it and trust it. It is estimated that it will cost 6 to 10 years for this to be achieved.
- All key functions should be filled by top experts in the relevant fields.
- Provide different communication strategies to reach the different DHH subgroups.
- It is essential that regular health care workers who look after the target group are comprehensively informed about these facilities.

5 | CONCLUSIONS

The problems that DHH people face in accessing health care are universal, but the possible solutions to alleviate these differ locally. There is a great need for facilities to collect and disseminate information to and about DHH patients. The information should be aimed at providing psycho-education for both the DHH persons themselves and the health care professionals concerning the specific needs and problems of this patient group.

CONFLICT OF INTEREST

The authors have no conflict of interest to declare.

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ENDNOTES

- ¹ (<http://www.barmherzige-brueder.at/pages/issn/gesundheitszentrumgehoerl>).
- ² Dovenschap is the largest independent interest group for Deaf people in the Netherlands.
- ³ The mill organization is a collaboration of seven interest groups/patient organizations in the Netherlands.

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