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Parents of children with Down syndrome and their experiences with the healthcare services

ORIGINAL ARTICLE

MARTE JOHANNE STEFFERUD

Faculty of Health Sciences
University of Tromsø – The Arctic University of Norway
She has contributed to the idea, design of the questionnaire, data collection, analysis and interpretation, literature searches, drafting and revision of the manuscript and approval of the submitted manuscript version.
Marte Johanne Stefferud, medical student.
The author has completed the ICMJE form and declares no conflicts of interest.

ANNE GRETHE EINANG

Hedmark Habilitation Service
Section of Paediatrics
Innlandet Hospital Trust
She has contributed to the design of the questionnaire, data collection and interpretation, and approval of the submitted manuscript version.
Anne Grethe Einang, special-needs educator, head of section and former board member of the Norwegian Network for Down Syndrome (NNDS).
The author has completed the ICMJE form and declares no conflicts of interest.

CLAUS KLINGENBERG

claus.klingenberg@unn.no
Department of Paediatrics and Neonatal Medicine
University Hospital of North Norway
and
Department of Clinical Medicine

University of Tromsø – The Arctic University of Norway
He has contributed to the idea, design of the questionnaire, data interpretation, literature searches, drafting and revision of the manuscript and approval of the submitted manuscript version.
Claus Klingenberg, specialist in paediatrics, senior consultant and professor of paediatrics.
The author has completed the ICMJE form and declares no conflicts of interest.

BACKGROUND
Children and adolescents with Down syndrome have a comprehensive need for follow-up in the primary and specialist healthcare services.

MATERIAL AND METHOD
In June 2019, we published a questionnaire on the Facebook group of the Norwegian Network for Down syndrome. The purpose was to investigate user experiences among parents of children and adolescents with Down syndrome in the age group 0–20 years, in their encounter with the healthcare services.

RESULTS
We received 174 responses. Those most satisfied were parents of children who received follow-up for secondary diagnoses such as vision problems, heart defects and endocrine disorders. Those least satisfied were parents of children with problems associated with behaviour, sleep and puberty. Approximately 6 out of 10 parents reported no negative experiences in their encounter with the healthcare services, but 29/161 (18 %) reported that the diagnosis of Down syndrome had contributed to treatment failure by the paediatrician or in the child rehabilitation service.

INTERPRETATION
The study indicates a need for improved follow-up of children and adolescents with Down syndrome, both in the primary and specialist healthcare services.

Main findings

In a survey of 174 parents of children with Down syndrome, approximately 6 out of 10 parents had no negative experiences with the healthcare services.

The parents were most satisfied with the follow-up of vision problems, heart defects and endocrine disorders, and least satisfied with the follow-up of psychiatric challenges and problems related to sleep and puberty.

Eighteen per cent of the parents reported to have experienced treatment failure by a paediatrician or in the child rehabilitation service.

Down syndrome is the single most common cause of intellectual disability in Norway (1). Over the last 20 years, 60–90 children with Down syndrome have been born each year (2). People with Down syndrome have complex medical and social needs. Parents of children with disabilities face challenges in obtaining the right medical support and help. Many of them work reduced hours to be able to follow up their child (3, 4). Good contact between the users and healthcare providers is important to promote the health of both child and parents. We have conducted a survey among parents of children and adolescents with Down syndrome. The objective of the study was to explore their experiences with various parts of the healthcare system, with a focus on follow-up procedures and any negative experiences they might have had.

Material and method

Since we were unable to find a validated questionnaire that thematically covered the aims of the study, we formulated our own. In June 2019, we posted the questionnaire (see the Appendix on tidsskriftet.no) as a weblink for the members of the Facebook group of the Norwegian Network for Down Syndrome. The group has approximately 4500 members, including persons with Down syndrome, their families/guardians and professionals. We later posted three reminders before the questionnaire was closed in October 2019.

The questionnaire contained 18 questions with one or more response alternatives, as well as a free-text field. The first part concentrated on background information about the child, including any secondary diagnoses. The second part focused on the parents' encounter with the healthcare services and their perception of the way in which their child was followed up. The response alternatives were presented as a five-point Likert scale. The final part of the questionnaire provided information on which parent responded and in what health region the family lived. The free-text responses were not systematically analysed, but used to elucidate topics that were insufficiently reflected in the questions with pre-defined response alternatives.

Statistical analyses

The data were transferred to SPSS. Main findings are reported descriptively. Inter-group comparisons were made with the chi-square test. A p-value < 0.05 was considered significant.

Ethics and data protection

In accordance with the reporting form of the Norwegian Centre for Research Data we concluded that the data could not be used to identify specific individuals (5). The Regional Committee for Medical and Health Research Ethics deemed the study to be exempt from the obligation of disclosure.

Results

A total of 174 parents with children aged 0–20 years completed the first part of the questionnaire, 161 (93 %) completed the second part and 157 (90 %) the third part. Mothers were the most frequent respondents (143/157; 91 %). Table 1 shows that 117/174 (67 %) of the children were younger than 10 years, and that 130/174 (75 %) had one or more secondary diagnoses, most commonly heart defects.

Table 1

Background information on 174 children and adolescents with Down syndrome in a survey on parental experiences in their encounter with the healthcare services.

Variable	Proportion
Age	
0–3	45 (25.9 %)
4–6	36 (20.7 %)
7–9	36 (20.7 %)
10–12	24 (13.8 %)
13–17	25 (14.4 %)
18–20	8 (4.6 %)
Common secondary diagnoses	
Heart defects	61 (35.1 %)
Otorhinolaryngologic disorders	49 (28.2 %)
Gastrointestinal disorders	44 (25.3 %)
Endocrine disorders	37 (21.1 %)
Obstructive sleep apnoea syndrome	27 (15.5 %)
Autism	7 (4.0 %)
Epilepsy	8 (4.6 %)

Table 2 shows that the parents were most satisfied with the follow-up of conditions such as vision problems, heart defects and endocrine disorders. However, eleven parents commented in the free-text field that they had to follow up and ask for routine check-ups themselves. The highest degree of dissatisfaction with the follow-up by the healthcare services was found in relation to psychiatric challenges and problems associated with sleep and puberty (Table 2). Eight parents commented in the free-text field that there was a poor level of knowledge regarding the association between health problems and behavioural disorders.

Table 2

Satisfaction among parents of children and adolescents with Down syndrome with the follow-up by the healthcare services of various possible secondary diagnoses/issues. The three conditions that received the highest and lowest scores are shown in bold type.

Diagnostic group	Very good or good	Neutral	Very poor or poor	Total, n[1]
Sleep	29 (30.5 %)	24 (25.3 %)	**42 (44.2 %)**	95
Puberty	5 (15.2 %)	16 (48.5 %)	**12 (36.4 %)**	33
Gastrointestinal	38 (37.3 %)	28 (27.5 %)	36 (35.3 %)	102
Otorhinolaryngology	91 (60.7 %)	34 (22.7 %)	25 (16.7 %)	150
Psychiatry	3 (6.7 %)	15 (33.3 %)	**27 (60.0 %)**	45
Epilepsy	7 (41.2 %)	9 (52.9 %)	1 (5.9 %)	17
Heart	**90 (90.9 %)**	9 (9.1 %)	0 (0 %)	99
Endocrine	**73 (63.5 %)**	27 (23.5 %)	15 (13.0 %)	115
Cancer	12 (60.0 %)	4 (20.0 %)	4 (20.0 %)	20
Vision	**122 (78.7 %)**	23 (14.8 %)	10 (6.5 %)	155

[1]Altogether 161 parents completed this part of the questionnaire, but the total number in the right-hand column depends on whether or not the parents had any experience with follow-up of their child in the area in question. Some had also been followed up without a disorder having been diagnosed, and the figures are therefore higher than in Table 1 for some conditions.

More parents (110/161; 68 %) were satisfied with the follow-up by the general practitioner (GP) or another medical specialist than with the follow-up by a paediatrician/child habilitation service (87/161; 54 %), $p = 0.008$. The parents were more satisfied with the knowledge level of the paediatrician/child habilitation service (112/161; 69 %) than with that of the GP (57/161; 35 %), $p < 0.001$. The parents of children without secondary diagnoses were more satisfied with the follow-up provided by the GP (32/39; 82 %) than the parents of children with secondary diagnoses (78/122; 64 %), $p = 0.034$. In the free-text comments, it emerged that three of the parents had not heard about the child habilitation service, and another six had difficulties in obtaining help from the service. Ten parents had left free-text comments about a lack of coordination and communication between various healthcare services.

Many parents reported to have had no negative experiences in their encounter with the GP (95/161; 59 %) or a paediatrician/child habilitation service (105/161; 65 %). However, 29/161 (18 %) parents reported that the diagnosis of Down syndrome had contributed to treatment failure by the paediatrician/child habilitation service. Nine parents commented that their worst experience was associated with the birth of the child and the attitudes in the maternity ward.

Discussion

The psychological burden on families with children with Down syndrome is well known (6), but no Nordic studies have yet investigated the parents' user satisfaction with the healthcare services. Well over one-half of the parents reported to be satisfied with the follow-up of their children by the primary and specialist healthcare services, but the study did reveal some potential for improvement.

Persons with intellectual disability have a preponderance of secondary diagnoses. In line with previous studies, the parents in our study felt it burdensome to have to take responsibility for check-ups themselves (3, 4). Eighteen per cent of the parents reported to have experienced 'treatment failure', most frequently in the specialist healthcare service. It is important for all healthcare professionals that follow up persons with Down syndrome to have knowledge about the follow-up of potentially serious secondary diagnoses (7).

The parents were least satisfied with the follow-up of issues related to sleep, behaviour/psychiatry and puberty. Such issues arise in somewhat older children with Down syndrome, and the appropriate healthcare providers to attend to these issues are less clearly defined. This may be a source of more uncertainty and less satisfaction among parents, and points to a need for more competence among health care providers about behavioural and mental problems in persons with intellectual disability (8).

The primary healthcare service has a key role in the follow-up of persons with Down syndrome. Our study indicates that parents appreciate good local follow-up. It was surprising to learn that some parents had never heard about the child habilitation service or had problems in establishing contact with the service, which is responsible for coordination of service provision and ensuring that there is regular follow-up (1, 8).

Many commented that when they received information about Down syndrome in the maternity ward, it was in a very demanding situation. This is known also from previous studies (9). Good recommendations are available regarding how healthcare professionals should communicate information about genetic disorders such as Down syndrome (10).

This study has some limitations. We do not know how many parents of children with Down syndrome are members of the Facebook group. We received responses from more than 160, but we are uncertain as to whether this sample is representative. Thus, there is a risk of selection bias. The secondary diagnoses were not specified in detail, and some questions may have been interpreted in different ways. However, the prevalence of heart defects, epilepsy and endocrine issues was in line with what is reported for patients with Down syndrome (11). In the youngest children in the study, behavioural and mental problems may not yet have arisen or been diagnosed. More than 90 % of those who responded to the survey were mothers, and the answers might have been different if more fathers had responded.

Conclusion

Although many parents are satisfied, the study indicates that there is a need for even better follow-up of children and adolescents with Down syndrome, both in the primary and specialist healthcare services.

We wish to thank all the parents who took the time to participate in this survey.

LITERATURE

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