

Assessing needs of families raising a child with a chronic health condition: the OBI-CZ study

A content validity study of the Family Support & Needs Inventory

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Abstract

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Background: Families raising a child with a chronic health condition face multiple challenges. Much is known about these challenges, however, little is known about the needs of these families and how healthcare professionals can support them in the most effective manner. Moreover, these needs vary for each family and situation. For families raising a child with a physical disability, a Dutch instrument to inventory their needs was developed previously: the OBI (*OndersteuningsBehoeften Inventarisatie [Family Support & Needs Inventory]*) checklist. It is expected that this instrument is also useful for families raising a child with a chronic health condition.

Aim: To determine if the OBI checklist is useful for families of children with a chronic health condition, and to validate the content of this instrument for this new population.

Method: The OBI checklist, which consists of 189 possible family needs, was assessed for its relevance by parents of children with a chronic health condition (n=21), and healthcare professionals (n=9) in two paediatric hospitals in the Netherlands. A content validity index was computed for each item in the OBI checklist, to rate each item's relevance. Additionally, missing items, strengths and weaknesses, and overall usefulness of the OBI checklist were assessed.

Results: Only 14 of the 189 items were judged as less relevant for this population. All other items were found reasonably to highly relevant. Especially items within the domains of 'diagnosis, development, and expectations', and 'medical treatment' were found highly relevant. The overall usefulness of the OBI checklist scored 7.55 out of 10.

Conclusion: The OBI checklist seems a suitable instrument for identifying needs of families raising a child with a chronic health condition, and can be of great value in family-centred care settings.

Recommendations: Further research is needed regarding family needs based on the child's diagnosis, and severity of the condition.

Keywords: family needs; family support; family-centred care; children with chronic health conditions

Introduction

Improvements in therapy, treatment, and care in developed countries have led to an increased prevalence of children and adolescents with a chronic health condition (van der Lee *et al.* 2007). In the Netherlands > 500000 children experience a chronic condition, encompassing 14% of all children in the Netherlands (Mokkink *et al.* 2007). A childhood disease or condition is considered chronic when it originates between 0 up to 18 years, lasts or is expected to last more than 3 months, and affects the child's normal age-appropriate activities (Perrin *et al.* 1993).

Families affected by childhood chronicity face multiple challenges. Parenting itself is a challenge; however, when facing children with a chronic health condition, parents need to adopt the role of medical expert, and care coordinator as well (Kratz *et al.* 2009). These parents need to acquire the necessary knowledge, skills, and organisation to take care of a child with a chronic disease (Ray 2002). Next to providing the best possible care for their chronically diseased child, parents also face challenges such as social isolation, finding time for personal needs, balancing the child's needs with siblings, coping with fear and anxiety, lack of understanding from others, adjusting expectations, and redefining normal family-life (Kratz *et al.* 2009).

It is important for healthcare professionals to support these parents in the challenges they face, especially since family-centred care has emerged as an important concept in paediatrics. The concept of family-centred care is based on the understanding that the family is the child's primary source of strength and support (American Academy of Pediatrics 2012). Family-centred approaches lead to better health outcomes and can enhance parents' confidence in their roles while taking care for their child (American Academy of Pediatrics 2012). In order to provide the best possible care for families with a child with a chronic health condition, it is essential to understand how healthcare professionals can support these families in the most effective manner. Previous research has shown that even paediatricians who provide a great deal of support and assistance to these families underestimate the unmet needs their patients' parents recognise (Perrin *et al.* 2000). These needs also vary for each individual family and situation: they depend in part on the particular condition of the child, its severity, the child's age, the parents' social circumstances, and the medical care arrangements available to the family (Perrin *et al.* 2000). According to Perrin *et al.* (2000) it is therefore important that paediatric practice systems include effective mechanisms to assess parents' opinions regarding the needs of their family, when raising a child with a chronic health condition.

For families raising a child with a physical disability, a Dutch instrument to inventory their needs was developed previously (Siebes *et al.* 2009). This instrument, called the OBI (*OndersteuningsBehoefte Inventarisatie [Family Support & Needs Inventory]*), is a checklist that helps professionals in paediatric rehabilitation to identify the needs of these families and to convert them into concrete guiding questions. It was expected that this instrument can also be useful for families raising a child with a chronic health condition. The content of this instrument was therefore validated in this new population.

Problem statement

Families raising a child with a chronic health condition face multiple challenges. Much is known about these challenges, however, little is known about the needs of these families and how healthcare professionals can support them in the most effective manner. Moreover, these needs vary for each family and situation. An effective instrument for identifying families needs of families raising a child

with a chronic health condition can therefore be of great value in today's family-centred care settings. The OBI checklist, which was originally intended for families raising a child with a physical disability, could be such an instrument. It can help healthcare professionals to identify needs of each family individually and to convert these needs into concrete guiding questions.

Aim

The objectives of this study were to determine if the OBI checklist is useful for families of children with a chronic health condition, and to validate the content of this instrument for this new target population. Moreover, this study provides the information that can be used to construct an OBI version with a content that suits the needs of families of children with a chronic health condition in the future, in order to communicate their needs with healthcare professionals.

Research questions

The questions asked were:

- *To what extent does the content of the OBI checklist match the needs of families raising a child with a chronic health condition?*
- *To what extent does the content of the OBI checklist depend on the diagnosis of the child?*
- *What are the strengths and weaknesses in using the OBI checklist for families raising a child with a chronic health condition?*

Method

A quantitative, descriptive, clinimetric, cross-sectional design was used to measure the content validity of the OBI checklist if used for families with a child with a chronic health condition. Participants were asked to fill out a questionnaire once, and were not submitted to any kind of intervention.

Participants

To measure content validity the judgement of experts was needed (Streiner & Norman, 2008). Both parents of children with a chronic health condition and paediatric healthcare professionals were considered experts in the field of family needs and took part in this study.

Participants were recruited in two paediatric hospitals in the Netherlands (a university teaching hospital in Utrecht and a non-academic teaching hospital in The Hague). In these hospitals children with a variety of chronic health conditions are treated. For this study there was access to parents of children with asthma, Diabetes Mellitus type 1 (DM-1), Inflammatory Bowel Diseases (IBD), and childhood Systemic Autoimmune Diseases (SAD; e.g. juvenile systemic lupus erythematosus, juvenile dermatomyositis, and juvenile scleroderma). Parents were asked to participate if they had a child with one of these conditions, in the age range 0–18 years, and who was living in the parent's home.

A variety of healthcare professionals from both hospitals, involved in the treatment and care of children with chronic health conditions, were asked to participate. It was aimed to get a sample that was representative for the healthcare system in the Netherlands.

Outcomes

The OBI checklist consists of 189 items of possible 'family needs' when raising a child with a physical disability. These needs are categorized in 13 domains (Table 1). Parents can indicate whether these needs are applicable to their situation with 'yes' or 'no'. There are no scores associated with the answers. The OBI checklist simply inventories if there is a need for something or not. To find out whether the needs in the OBI checklist are also applicable for parents raising a child with a chronic health condition, each item was assessed for its relevance. Participants were asked to score the relevance of each item on a 4-point ordinal scale which was added to all items in the OBI checklist: 1=*not relevant*, 2=*somewhat relevant*, 3=*quite relevant*, 4=*highly relevant* (Davis 1992).

After rating each item for its relevance, all participants were asked if they missed any needs in the OBI checklist. Additionally, they were asked what they think the strengths and weaknesses of the OBI checklist are. Finally, all participants were asked to rate the usefulness of the OBI checklist for families raising a child with a chronic health condition.

The complete questionnaire about the OBI checklist can be found in Appendix 1 and is referred to as the OBI-CZ (OBI-*Chronisch Zieken* [*OBI-chronic health condition*]) checklist.

Procedure

In both hospitals eligible parents were asked by their paediatrician, or nurse specialist whether the researcher could contact them for the study. When they agreed, they were entered tentatively into the study sample. They received a package with an information letter, a consent form, the OBI-CZ checklist, and a prepaid return envelope. The information letter contained all information about the study, and its procedures. Parents were asked to sign the consent form, and to fill out the OBI-CZ checklist within two weeks. Parents were able to do this in the privacy of their own home, and on a time of preference. In case the approached parents did not respond within two weeks, the researcher gave them a telephone reminder. Once the questionnaire was returned, parents were considered as participants in the study.

Healthcare professionals were invited by the researcher to participate. After giving their consent, they also received an information letter, and were also asked to fill out the questionnaire within two weeks.

Sample size

To determine content validity a minimum of five experts would provide sufficient level of control for chance agreement (Lynn 1986). A maximum number of experts is not established, however, it is unlikely to include >10 (Lynn 1986). Therefore, it was attempted to enrol 10 paediatric healthcare professionals as well as 10 parents for each chronic health condition, forming four groups based on the diagnosis of the child and one group of healthcare professionals (n=50).

Data analysis

The content validity of the different items of the OBI-CZ checklist was based on parents' and healthcare professionals' ratings of item relevance. A content validity index (CVI) was computed for each item on the OBI-CZ checklist, resulting in an item-level content validity index (I-CVI) (Polit *et al.* 2007). The I-CVI was computed by dividing the number of participants who gave an item a rating of 3 or 4 on the 4-point scale, by the total number of participants who rated the item, resulting in the proportion of agreement about relevance. Taking into account a certain amount of chance

agreement an I-CVI of .78 or higher was needed for an item to be judged as having excellent content validity, regardless of the number of experts (Polit *et al.* 2007). Items with an I-CVI of .50 or less in all groups were considered as having less relevance for this population. Items with an I-CVI between .50 and .78 were judged as having reasonable content validity.

A CVI can also be computed for an overall scale by computing the I-CVI of each item, and then calculating the average I-CVI across the items (Polit *et al.* 2007). This was here used to compute an average I-CVI per domain of the OBI-CZ checklist, providing information about the overall relevance of the domain.

Results of the I-CVI were analysed for all groups together and per group (healthcare professionals and the four groups based on the diagnoses of the child), so differences between groups could be identified. The Kruskal-Wallis test was used to identify significant differences in the raw ordinal data between the five groups.

The usefulness of the OBI-CZ checklist was rated by the participants on a scale from '*not useful at all*' to '*very useful*', expressed in a scale from 1 to 10, so the grading could be expressed by a mean with standard deviation.

What participants described as missing 'needs' on the OBI-CZ checklist, and the strengths and weaknesses they mentioned were clustered and labeled in orderly tables.

Ethical considerations

Due to its character, this study is not subject to the Medical Research Involving Human Subjects Act (WMO). Nevertheless, this study was submitted for review to the accredited medical research ethics committee of the University Medical Centre Utrecht and was assigned '*not subject to the WMO*'.

Results

Description of the sample

Initially, 40 parents, and 10 healthcare professionals agreed to participate. Eventually, 30 participants completed the questionnaire: 9 healthcare professionals, and 21 parents of a child with a chronic health condition (SAD n=6, DM-1 n=5, IBD n=6, and asthma n=4) (Figure 1). The response rate for each group was: SAD=60%, DM=33.3%, IBD=85.7%, asthma=50%, and healthcare professionals=90%. Participating parents varied in age from 33 to 52 years, and 95% were mothers. Their children varied in age and time since diagnoses. Two-parent families represented 81% of the sample and most families had two children. All of the families had only one child with a chronic health condition. Further, these families represented a variety in socioeconomic status based on family income, and educational level (Table 2). The healthcare professionals represent a variety of professionals working with children with chronic health conditions in the healthcare system of the Netherlands: one paediatrician, four paediatric nurses, one nurse specialist on childhood diabetes, one child psychologist, one paediatric physical therapist, and one socio-pedagogical care worker. The healthcare professionals were all female, varied in age from 26 to 58 years, and had 5 to 37 years of work experience with chronically ill children (Table 3).

Overall analysis of the CVI

The assessment of relevance for each item in the OBI-CZ checklist can be found in Appendix 2. The average I-CVI per domain is presented in Table 4. Needs within the domains of 'diagnosis, development, and expectations', and 'medical treatment' were found highly relevant, with an average I-CVI of .84, and .86 respectively. These two domains hold 17 of the 31 items in the OBI-CZ checklist with an I-CVI of $>.78$. The lowest average I-CVI (.52) was found in the field of 'transportation'. None of the items in this domain had an I-CVI $>.78$, where in most other domains high outliers of the I-CVI were found. Only the domains 'medical aids, adaptations, and expectations', 'the family', and 'leisure' had no high outliers (I-CVI $>.78$) too.

Two items on the OBI-CZ checklist scored an I-CVI of 1, meaning all participants found these items highly relevant. These items express the information need about the future development of the child and finding a specialised physician. Other items with exceptional high (I-CVI $>.85$) or low (I-CVI $<.50$) scores can be found in Table 5.

Subgroup analysis of the CVI

Results of the I-CVI were also analysed per group (Table 4). Healthcare professionals scored the highest average I-CVI per domain (all $>.77$). The lowest results were found in the group of parents of children with DM-1, where 11 of the 13 domains scored an average I-CVI $<.50$. The group of parents of children with SAD rated only one domain $<.50$ (transportation), and parents of a child with IBD rated all the domains $>.50$. Parents of children with asthma rated 7 out of 13 domains $<.50$. Summarising, the highest scores were given by healthcare professionals, and parents of a child with IBD or SAD.

Significant differences between the groups in the ratings given to the items were found in 9 out of 13 domains (Table 4). Most differences were found in the domain of 'the family', where all items differed significantly between the groups. Average I-CVI scores $<.30$ were here found in the groups of parents of a child with DM-1 or asthma, while healthcare professionals and parents of a child with SAD or IBD rated the items with an average I-CVI of $>.69$.

Appraisal of the OBI

Participants rated the usefulness of the OBI-CZ checklist on a scale from 1 (*'not useful at all'*) to 10 (*'very useful'*). The overall mean score was 7.55. The scores varied somewhat between the groups, although not significant (Table 6).

Participants expressed several strengths and weaknesses of the OBI-CZ checklist. Strong points were its completeness, the involvement of the whole family, and the attention paid to the medical treatment of the child. The length of the checklist was found a disadvantage. Strengths and weaknesses that were mentioned more than once are presented in Table 7.

Only one participant expressed a missing item on the OBI-CZ checklist: help by finding a job after staying at home taking care of the child.

Discussion

All items of the OBI-CZ checklist were assessed for their relevance for families raising a child with a chronic health condition. Only 14 of the 189 items scored an I-CVI $<.50$, meaning that almost all items were found to be at least of reasonable relevance for this population. For an item to be judged as having excellent content validity, Polit *et al.* (2007) stated that an item should have an I-CVI score of at least .78. In this study, this is only the case in 31 of the 189 items. This does not mean that the other items are not valid enough to stay in the OBI-CZ checklist. The CVI was originally intended for measuring content validity of items in a scale. The OBI checklist does not measure one concept, it inventories possible family needs. Since family needs vary for each individual situation, not all items have to be relevant for all families. An I-CVI of $>.50$ means that still $>50\%$ of the respondents found the item to be relevant for families raising a child with a chronic health condition, indicating that >5 out of 10 families could have a need for this particular item. It is therefore justifiable that all items with at least reasonable content validity stay in the OBI-CZ checklist.

Needs within the domains of 'diagnosis, development, and expectations' and 'medical treatment' were found highly relevant. These findings are consistent with those of Farmer *et al.* (2004), who found that the most frequently endorsed unmet needs of families with a child with a chronic health condition are in the field of information about services for their child and ways to promote the child's health and development. Also Perrin *et al.* (2000) found the highest scores on unmet needs of families with a child with a chronic health condition in information needs about the child's condition and its treatment, development, and what to expect as the child gets older.

Extremely low scores that were found in the field of transportation, special equipment or playground, respite care, placement elsewhere, or holiday camps are probably because the children in this sample are not mobility impaired. Palisano *et al.* (2010) found that parents of children who use wheeled mobility were more likely to express needs for home modifications, equipment, toys and services, respite care, babysitting, and community activities.

Overall, healthcare professionals gave the highest ratings of relevance for the items in the OBI-CZ checklist. This is inconsistent with the findings of Perrin *et al.* (2000) where paediatricians ($n=11$) underestimated parents' needs. Possibly, awareness of family needs could have been risen since the concept of family-centred care has become increasingly important. Moreover, our sample does not only include paediatricians, but other healthcare professionals as well.

In the four groups based on diagnosis of the child, the highest response rate came from parents of children with IBD or SAD. These parents also gave the highest ratings of relevance of the items in the OBI-CZ checklist. According to Farmer *et al.* (2004), predictors of higher unmet family needs are lower socioeconomic status (SES), worse child functioning, lower perceptions of social support, lower satisfaction with healthcare services, and greater perceptions of family burden. Correspondingly, Perrin *et al.* (2000) found that, independent of diagnostic category, parents of children with more severe conditions indicated a larger number of needs. Children's age does not seem to make a difference in predicting the number of family needs (Farmer *et al.* 2004, Palisano *et al.* 2010). In our sample, parents of children with IBD or SAD scored somewhat lower on SES based on family income and educational level, however this is a small sample, and there were missing data on family income. What is more, we did not differentiate on the severity of the child's condition, making it possible that children in DM-1 and asthma groups had a less severe condition. One mother of a child with DM-1

wrote: *“looking at this list, it strikes me that we definitely do not feel that we live with a child with a chronic health condition. Maybe because everything runs so smoothly, also with school, hobbies, and social contacts.”* This could also explain why healthcare professionals gave overall higher scores. They possibly had a variety of chronic health conditions and severities in mind when rating the items’ relevance.

Some limitations must be taken into account when looking at the results. Firstly, results come from a small sample and we did not differentiate on severity of the condition of the child. Secondly, the response rate and group size varied between the groups and no information was collected from non-responders. Finally, only four types of chronic health conditions were included in the sample, limiting generalisability to other chronic health conditions.

Conclusion & Recommendations

The OBI-checklist was found useful for identifying needs of families raising a child with a chronic health condition by healthcare professionals as well as parents of children with a chronic health condition. Only 14 of the 189 items of the OBI checklist were judged as less relevant for this population. All other items were found reasonable to highly relevant. Especially items within the domains of ‘diagnosis, development, and expectations’, and ‘medical treatment’ were found highly relevant.

Strengths of the OBI checklist are its completeness and the involvement of the whole family. A limitation is the length of the checklist.

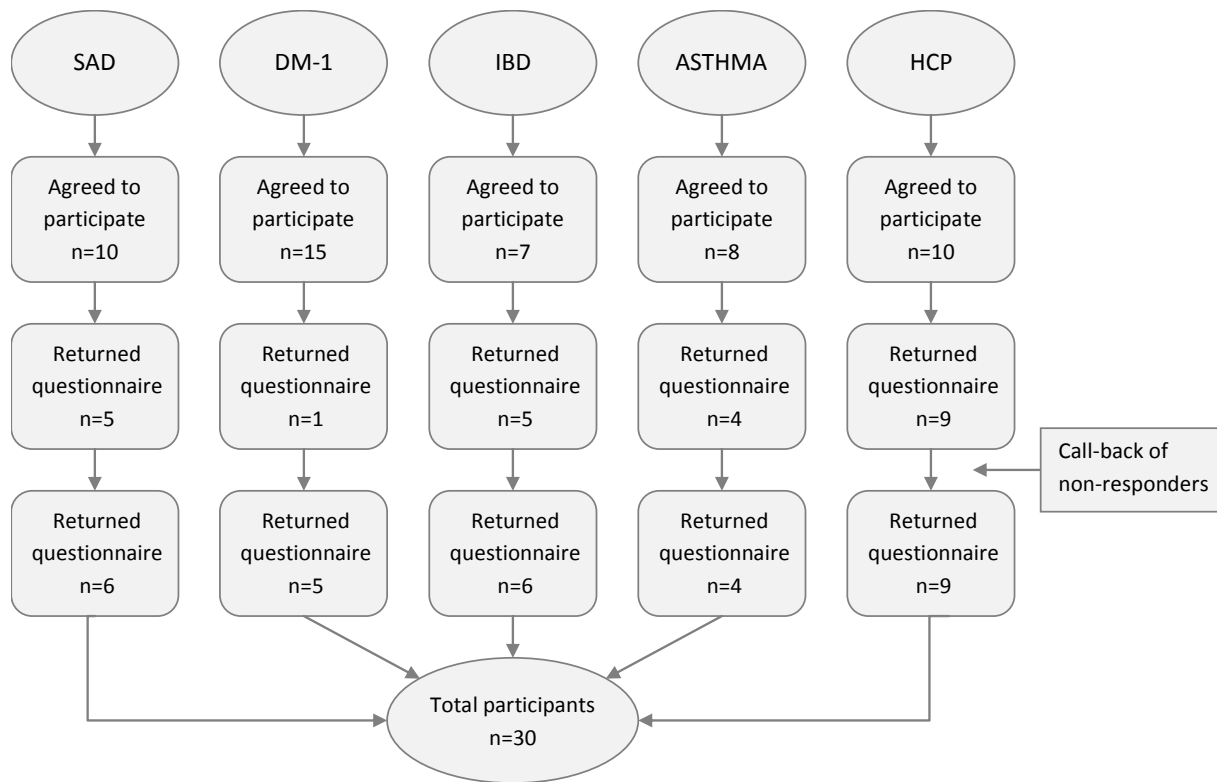
Differences were found in the relevance of family needs based on the diagnosis of the child, possibly due to the severity of the child’s condition. However, this being a small sample, more research in this field is needed.

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Figures and tables

Figure 1: Flowchart of participants



SAD=Systemic Autoimmune Disease, DM-1= Diabetes Mellitus type 1, IBD= Inflammatory Bowel Disease, HCP=Healthcare Professional.

Table 1: Domains of the OBI checklist

Domain of family needs	Number of items
(A) Diagnosis, development, and expectations	6
(B) Medical treatment	16
(C) Allied healthcare	19
(D) Day care, school, and work	17
(E) Medical aids, adaptation, and facilities	17
(F) Practical support at home	16
(G) The family	16
(H) Parenting	17
(I) Social, and psychological support	22
(J) Informing others	9
(K) Leisure	9
(L) Transportation	11
(M) Law, legislation, and financial support	14

Table 2: Characteristics of participating parents by diagnosis of the child

Variable	SAD n=6	DM-1 n=5	IBD n=6	Asthma n=4
Mothers	100%	100%	83%	100%
Parents' age range in years (median)	34-46 (39.5)	33-50 (42.0)	35-48 (46.0)	41-52 (44.5)
Childs' age range in years (median)	7-17 (10.5)	5-14 (11.0)	13-18 (16.5)	9-15 (13.0)
Time since diagnosis in months (median)	16-128 (42.5)	34-128 (68.0)	18-56 (28.0)	35-144 (89.5)
Number of children in family (median)	2-4 (2)	1-3 (3)	1-5 (2)	2-2 (2)
Two-parent families	67%	100%	83%	75%
Family income				
< €20000.	17%	–	33%	–
€20000 - €30000	17%	–	–	–
€30000 - €40000	–	20%	–	–
€40000 - €50000	–	–	–	–
> €50000	33%	60%	33%	75%
Missing	33%	20%	33%	25%
Educational level				
Low	17%	–	33%	–
Middle	33%	60%	50%	25%
High	50%	40%	17%	75%

SAD=Systemic Autoimmune Disease, DM-1= Diabetes Mellitus type 1, IBD= Inflammatory Bowel Disease.

Table 3: Characteristics of participating healthcare professionals

Variable	Healthcare professionals (n=9*)
Female	100%
Age range in years (median)	26-58 (47.0)
Work experience in years (median)	5-37 (11.0)

*n=1 paediatrician, n=4 paediatric nurses, n=1 nurse specialist on childhood diabetes, n=1 child psychologist, n=1 paediatric physical therapist, n=1 socio-pedagogical care worker.

Table 4: Average item-level content validity index (I-CVI) per domain for all groups together and per group

Domain of family needs (number of items)		Average I-CVI						Significant* items (%)
		Total	SAD	DM-1	IBD	Asthma	HCP	
(A) Diagnosis, development, and expectations	(6)	.84	.86	.77	.77	.92	.89	1 (17%)
(B) Medical treatment	(16)	.86	.82	.77	.88	.81	.96	-
(C) Allied healthcare	(19)	.67	.78	.45	.65	.42	.87	7 (44%)
(D) Day care, school, and work	(17)	.70	.73	.47	.63	.57	.91	6 (35%)
(E) Medical aids, adaptation, and facilities	(17)	.61	.58	.31	.61	.69	.77	-
(F) Practical support at home	(16)	.57	.63	.25	.57	.34	.81	3 (19%)
(G) The family	(16)	.66	.69	.15	.86	.30	.95	16 (100%)
(H) Parenting	(17)	.69	.80	.41	.75	.37	.87	7 (41%)
(I) Social, and psychological support	(22)	.64	.63	.38	.73	.40	.85	9 (41%)
(J) Informing others	(9)	.70	.74	.38	.63	.64	.93	3 (33%)
(K) Leisure	(9)	.61	.61	.40	.50	.39	.88	1 (11%)
(L) Transportation	(11)	.52	.48	.20	.51	.34	.83	-
(M) Law, legislation, and financial support	(14)	.70	.60	.40	.75	.61	.93	-

Total=all groups together, SAD=Systemic Autoimmune Disease, DM-1= Diabetes Mellitus type 1, IBD= Inflammatory Bowel Disease, HCP=Healthcare Professional.

*p <.05

Table 5: Items with an exceptional high or low content validity index (I-CVI)

Exceptional high I-CVI scores (>.85)	I-CVI
The future development of my child	1
Finding a specialised physician	1
Procedures in the health care facility around treatment	.97
Medical treatments that benefit my child (in the future)	.97
New medical developments	.97
Accessibility of our physician	.97
Options for medication	.97
The physical condition of my child	.93
Preparing my child to go to the hospital	.93
Explanation of results of medical examinations	.90
Access to the medical files of my child	.90
The school performance of my child	.90
Explaining the chronic health condition to my child	.90
Explaining the chronic health condition of my child to siblings	.87
The current development of my child	.87
Choosing the right practitioners	.87
Providing the 'daily' medical care for my child	.87
Supporting my child with having a chronic health condition	.87
Health insurance coverage	.87
Administer medication	.86
Low I-CVI scores (<.50)	I-CVI
Speak my child's therapists more often	.48
Specialised day care for my child	.48
Special equipment that benefits the whole family	.48
Holiday camps for my child	.47
Transporting my child together with other children	.46
Respite care	.45
Transport for my child to respite care	.45
Alternative medicine	.43
Religious support	.43
Transport for my child to go to day care	.41
An adapted suitable playground for my child	.40
Possibilities for domestic help	.38
Placement of my child, or living elsewhere	.31
Keeping my administration in order	.28

Table 6: Rating of usefulness of the OBI-CZ checklist expressed in a scale from 1 to 10, per group

SAD	DM-1	IBD	Asthma	HCP	
mean (SD)	mean (SD)	mean (SD)	mean (SD)	mean (SD)	p-value
8.50	7.00	7.50	6.25	7.87	.207
(SD=1.643)	(SD=.707)	(SD=2.074)	(SD=2.062)	(SD=.835)	

SAD=Systemic Autoimmune Disease, DM-1= Diabetes Mellitus type 1,

IBD= Inflammatory Bowel Disease, HCP=Healthcare Professional.

SD=Standard Deviation.

Table 7: Strengths and weaknesses of the OBI-CZ checklist

Strengths	N
Complete list	10
Involves the whole family	6
Attention for medical treatment	6
Raises awareness	4
Attention for emotional, and psychological support	3
Clear list	2
Attention for contact with physician	2
Attention for the coordination of care	2
Weaknesses	N
Very long list	5
Not always very clear/difficult to use	2
Some items overlap	2

N=Number of participants who mentioned the strength or weakness

Appendix 1: The OBI-CZ checklist

Available through the author.

Appendix 2: Content validity index per item (I-CVI)

	I-CVI >.78	I-CVI <.78 >.50	I-CVI <.50
Family needs			
<i>(A) Diagnosis, development, and expectations</i>			
A1 Causes and/or heredity of the condition	.80		
A2 The physical condition of my child	.93		
A3 The physical limitations of my child	.83		
A4 The current development of my child	.87		
A5 The future development of my child	1		
A6 Growth and development of healthy children		.62	
<i>(B) Medical treatment</i>			
B1 Procedures in the health care facility around treatment	.97		
B2 Preparing my child to go to the hospital	.93		
B3 Someone to guide and inform us step by step	.83		
B4 Explanation of results of medical examinations	.90		
B5 Access to the medical files of my child	.90		
B6 Medical treatments that benefit my child (in the future)	.97		
B7 Medical possibilities abroad		.73	
B8 New medical developments	.97		
B9 Finding a specialised physician	1		
B10 Accessibility of our physician	.97		
B11 Second opinion		.70	
B12 A specialised dentist		.52	
B13 Options for medication	.97		
B14 Administer medication	.86		
B15 Providing the 'daily' medical care for my child	.87		
B16 Aftercare after discharge from the hospital		.73	
<i>(C) Allied health care</i>			
C1 The therapeutic treatment/counselling of my child		.73	
C2 Treatment options for my child		.72	
C3 Special or exceptional treatment options		.64	
C4 Possibilities for home treatment		.57	
C5 House call from therapists		.67	
C6 Treatment options closer to home		.67	
C7 Choosing the right practitioners	.87		
C8 Fit home exercises into daily routine		.77	
C9 Stimulating the physical development of my child		.77	
C10 Practical advice for the home situation		.53	
C11 School visits from therapists		.69	
C12 Speak my child's therapists more often			.48
C13 Improving communication between different practitioners		.69	
C14 Explanation of written reports		.60	
C15 Finding a balance between therapy, school, and play	.83		
C16 Aftercare after completing the treatment		.66	
C17 Regular checkups by my child's practitioners		.76	
C18 Nutrition information for my child		.73	

	I-CVI >.78	I-CVI <.78 >.50	I-CVI <.50
Family needs			
C19 Alternative medicine			.43
<i>(D) Day care, school, and work</i>			
D1 Attending a regular day care centre by my child		.52	
D2 Specialised day care for my child			.48
D3 Finding a suitable school for my child		.72	
D4 Admission to regular education	.83		
D5 Admission to special education		.72	
D6 Attending a regular school by my child		.77	
D7 Options for additional help with schoolwork	.79		
D8 The education program of my child		.76	
D9 The school performance of my child	.90		
D10 Attending regular after school care		.55	
D11 Options for specialised after school care		.52	
D12 Possible professions		.66	
D13 Suitable educational programs		.76	
D14 Internships and future employers		.72	
D15 Speak my child's teachers more often		.77	
D16 Handling problems at school		.76	
D17 Suitable daytime activities after school		.69	
<i>(E) Medical aids, adaptations, and facilities</i>			
E1 Options in medical aids		.77	
E2 Special equipment that benefits the whole family			.48
E3 Adaptations, or facilities to take a family trip		.55	
E4 Testing medical aids before application		.59	
E5 Application of medical aids		.63	
E6 Training or explanation of medical aids		.67	
E7 Adjusting small things around the house by ourselves		.62	
E8 Suitable/adaptive toys		.55	
E9 Adaptive clothing or shoes		.57	
E10 Facilities in our neighbourhood		.62	
E11 Facilities that my child might need in the future		.59	
E12 Financing medical aids, adaptations or facilities		.77	
E13 Facilities on more than one location		.52	
E14 Special aids at school, internship, and work		.69	
E15 Adapting my home to my child's needs		.62	
E16 Financing adapting my home		.62	
E17 Finding a suitable home		.55	
<i>(F) Practical support at home</i>			
F1 Care coordination around my child	.83		
F2 Physical care of my child		.52	
F3 Taking care of the child with the whole family		.66	
F4 A suitable sitter for my child		.59	
F5 Tangible support		.66	
F6 A sitter for other children in the family		.62	
F7 Possibilities of a personal health budget		.76	
F8 Someone who takes over the care for my child		.64	

	I-CVI >.78	I-CVI <.78 >.50	I-CVI <.50
Family needs			
F9 Someone who helps with the care of my child outside the home		.66	
F10 Possibilities for domestic help			.38
F11 Possibilities for family care support		.52	
F12 Keeping my administration in order			.28
F13 Respite care			.45
F14 Combining the care for my child with my work		.72	
F15 Organising daily affairs of the family		.52	
F16 Placement of my child, or living elsewhere			.31
(G) The family			
G1 Running a household with a child with a chronic health condition		.67	
G2 Creating family time		.60	
G3 Talking with my partner about affairs concerning my child and the condition		.67	
G4 Talking with family about affairs concerning my child and the condition		.60	
G5 Treating each other with respect as a family		.73	
G6 Talking problems and finding solutions together		.77	
G7 Support each other in difficult times		.76	
G8 The influence of the child's condition on relationships		.73	
G9 Coordinating household chores and care tasks within in the family		.55	
G10 Recognising behavioural changes in other family members		.70	
G11 Tips on how to handle behavioural changes in other family members		.67	
G12 Finding consensus with my partner on raising my child		.60	
G13 Raising my other children		.60	
G14 Dividing attention between special needs of my child and my other children		.67	
G15 Extra attention for the development of my other children		.70	
G16 Supporting siblings in handling their chronically ill sibling		.59	
(H) Parenting			
H1 Following the development of my child	.83		
H2 Raising my child		.73	
H3 Parenting support at home		.63	
H4 Playing with my child		.53	
H5 Suitable daily activities for my child		.66	
H6 Communicating with my child		.70	
H7 Communication aids for my child		.55	
H8 The emotional needs of my child		.73	
H9 The intellectual needs of my child		.70	
H10 Handling the sexuality of my child		.62	
H11 Teaching my child		.67	
H12 Handling the behaviour of my child		.77	
H13 Helping my child interact with other family members		.70	
H14 Teaching my child to interact with other children		.67	
H15 Promoting social contacts of my child		.73	
H16 Handling sleeping problems of my child		.66	
H17 Handling eating problems of my child		.77	
(I) Social, and psychological support			
I1 Sharing worries about my child with my partner		.67	

	I-CVI >.78	I-CVI <.78 >.50	I-CVI <.50
Family needs			
I2 Sharing worries about my child with my family		.67	
I3 Sharing worries about my child with the extended family		.67	
I4 Sharing worries about my child with friends		.57	
I5 Dealing emotionally with the condition of my child	.80		
I6 Supporting my child coping with having a chronic health condition	.87		
I7 Emotional/psychological support from a professional for myself		.57	
I8 Emotional/psychological support from a professional for siblings		.55	
I9 Emotional/psychological support from a professional for my partner		.50	
I10 Religious support			.43
I11 Meeting other parents with a chronically ill child		.72	
I12 Reading experience stories of other parents with a chronically ill child		.66	
I13 Sibling support groups		.53	
I14 Parenting groups		.50	
I15 Understanding and support from people around me		.77	
I16 Assertiveness training		.53	
I17 Finding time for myself		.60	
I18 Finding time for my partner		.57	
I19 Finding time for other children in the family		.70	
I20 A regular contact person who coordinates the care program around the family		.67	
I21 Advocating for my child		.77	
I22 Communicating with organisations, therapists, and physicians	.80		
(J) Informing Others			
J1 Explaining the chronic health condition to my child	.90		
J2 Explaining the chronic health condition of my child to siblings	.87		
J3 Explaining the chronic health condition of my child to family and friends		.67	
J4 Explaining the chronic health condition of my child to other children		.67	
J5 Informing and advising family and friends about my child		.73	
J6 Tips about how volunteers can handle my child's special needs		.73	
J7 Discussing the special needs of my child at work		.69	
J8 Reacting to questions from acquaintances or strangers about my child		.53	
J9 Handling reactions of people on the streets		.50	
(K) Leisure			
K1 Finding suitable leisure activities for the family		.67	
K2 Continuing 'old' hobbies		.57	
K3 Finding suitable leisure activities for my child		.77	
K4 Finding suitable activities for my child with other healthy children		.73	
K5 Finding suitable activities for my child with other chronically ill children		.60	
K6 Finding suitable activities for siblings to undertake with my child		.57	
K7 Organising a family holiday		.67	
K8 Holiday camps for my child			.47
K9 An adapted suitable playground for my child			.40
(L) Transportation			
L1 Transportation options for the whole family		.53	
L2 Transportation options for my child		.55	
L3 Transporting my child together with other children			.46

	I-CVI >.78	I-CVI <.78	I-CVI <.50
Family needs		>.50	
L4 Transporting my child safely		.62	
L5 Travelling by public transport with my child		.59	
L6 Bike riding with my child		.53	
L7 Transport for my child to go to school		.59	
L8 Transport during school activities		.52	
L9 Transport for my child to go to day care			.41
L10 Transport for my child to respite care			.45
L11 Discussing problems around transportation of my child		.52	
<i>(M) Law, legislation, and financial support</i>			
M1 Health insurance coverage	.87		
M2 Coverage from the Exceptional Medical Expenses Act		.73	
M3 The required indication for the Exceptional Medical Expenses Act		.72	
M4 Coverage from the Social Support Act		.57	
M5 Applying for a personal health budget		.60	
M6 Managing a personal health budget		.60	
M7 Applying for an Individualised Education Program		.70	
M8 Applying for a compensation for disabled children living at home		.62	
M9 Tax deductions		.72	
M10 Law and legislation around health care benefits		.76	
M11 Exploiting financial arrangements applicable for our situation	.80		
M12 Possible funding		.67	
M13 Law and legislation around care leave		.73	
M14 Complaints procedures		.67	

Appendix 3: Nederlandse samenvatting

De hulpbehoefte en hulpvraag van gezinnen waarin een kind met een chronische ziekte opgroeit: de OBI-CZ studie

*Een studie naar de inhoudsvaliditeit van de **OndersteuningsBehoeftelInventarisatie***

Inleiding: Gezinnen waarin een kind met een chronische ziekte opgroeit worden geconfronteerd met uiteenlopende uitdagingen. Er is veel bekend over deze uitdagingen, maar er is minder bekend over de behoeften van deze gezinnen en hoe zorgprofessionals hen het beste kunnen ondersteunen. Daarbij variëren deze behoeften voor elk gezin en elke situatie. Voor gezinnen waarin een kind met een lichamelijke beperking opgroeit is een checklist ontwikkeld om de ondersteuningsbehoeften van deze gezinnen in kaart te brengen: de OBI (**OndersteuningsBehoeftelInventarisatie**). Deze checklist kan ook bruikbaar zijn voor gezinnen met een kind met een chronische ziekte.

Doel: Bepalen of de OBI checklist bruikbaar is voor gezinnen waarin een chronisch ziek kind opgroeit en de inhoud van deze lijst valideren voor deze nieuwe populatie.

Methode: De OBI checklist, die bestaat uit 189 potentiële ondersteuningsbehoeften, werd beoordeeld op relevantie door ouders van kinderen met een chronische ziekte (n=21) en zorgverleners (n=9) in twee kinderziekenhuizen in Nederland. Een inhoudsvaliditeitsindex werd bepaald voor elk item op de OBI checklist, om van elk item de relevantie te beoordelen. Daarbij werden ontbrekende items, plus- en minpunten en de bruikbaarheid van de OBI checklist in kaart gebracht

Resultaten: Slechts 14 van de 189 items werden als minder relevant voor deze populatie beoordeeld. Alle andere items werden vrij tot zeer relevant gevonden. Met name de items binnen de gebieden 'diagnose, ontwikkeling en verwachtingen' en 'rondom de medische behandeling' werden zeer relevant gevonden. De algehele bruikbaarheid van de OBI checklist scoorde 7,55 uit 10.

Conclusie: De OBI checklist lijkt een geschikt instrument om hulpbehoeften van gezinnen waarin een kind met een chronische ziekte opgroeit in kaart te brengen en kan van grote waarde zijn binnen de hedendaagse gezinsgerichte zorg.

Aanbevelingen: Vervolgonderzoek naar ondersteuningsbehoeften van gezinnen gebaseerd op de diagnose van kind en de ernst van de aandoening is nodig.

Trefwoorden: ondersteuningsbehoeften; kinderen met een chronische ziekte; gezinsgerichte zorg; hulpvragen; gezinnen