



Dietitians of Canada

Les diététistes du Canada

Paediatric Nutrition Network

March 2003

Development of Nutrition Screening Checklist for Children with Special Needs

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BACKGROUND

Eating is so easy and natural that we sometimes take it for granted. Mealtimes are also times shared with family and friends. However, for children with special needs, the simple act of eating can present daily challenges for both parent and child. Eating may become associated with fear, stress and discomfort. As many as 40 % of children with special needs in the U.S. could be at nutritional risk (0,1). Common nutrition concerns seen in children with special needs¹ (CSN) include growth and weight issues, oral feeding difficulties, nutrient deficiencies and accessibility of foods or formula (0, 1,3,4,5 6,7). When these concerns are not addressed, it can compound a child's disability, decrease quality of life and increase the cost of interventions, other therapies and support. (3,4) The number of CSN in Canada was estimated to be 7.7% of children aged 0-19 years old in the 1996 Canada Population Health Survey (2).

However, not all CSN will require nutrition intervention. Therefore, we recognized that there was a need to develop a nutrition screening tool to identify which CSN in the community would benefit from intervention. Often there is limited accessibility to a dietitian for nutritional assessment or consultation so a self-administered nutrition screening checklist could assist health professionals to determine which children would benefit from nutrition intervention, and use dietitian resources most efficiently and effectively. (8,9, 10,11).This article will describe the development of a new tool the Parent Nutrition Screening Checklist (PNSC) for parents of children with special needs age 1 to 18 years. The development of this tool followed the template proposed by Keller et al (12) which outlines a systematic tool development process. It has also been an enlightening experience for the research team combining the expertise of dietitians with the developmental psychologists. There was also the added challenge of recruiting subjects given the small diverse population of CSN (2).

GETTING STARTED

Determine what you want to measure and what are the criteria to meet your needs¹²

The tool was needed to screen for nutritional risk amongst CSN aged 1 to 18 years in the community setting. We started with the community to define the setting for development and validation of the screening tool. Later, clinic and hospital settings should be considered for further testing. Since the parent is often the first to notice that his/her child is experiencing difficulties with their food intake and whether their child has nutritional and developmental problems (13), it was determined that the tool should be completed by the parent. The tool

¹ The term "children with special needs" describes a wide variety of conditions: neuromotor disabilities (e.g. cerebral palsy), complex developmental and behavioural disabilities and special health needs like brain injury, Downs syndrome, spina bifida, muscle diseases, children dependent on medical technology, children with prenatal exposure to alcohol and other drugs, Autism Spectrum Disorder(1,2,3)

needed to be specific to this population, reliable, valid and responsive to level of concern and changes in nutritional status of the child.

Review the literature for potential tools. Critique the tools from your literature search and compare with your criteria 12.

We conducted a literature search and consulted other dietitians and health professionals to determine what tools had already been developed. Several nutrition screening questionnaires were reviewed but did not fit our criteria either because they were developed for health professionals rather than parents or the questions were too complex or were not a validated tool (8,9). Other published parent nutrition questionnaires/checklists reviewed, were specific to age or condition e.g. concentrating only on infancy and early childhood (14) or eating behaviour (15).

In 1994, an easy to use validated survey, the PEACH (Parent Eating and Nutrition Assessment for Children with Special Health Needs) was developed.(16) This instrument, completed by parents, consisted of 17 simple questions using YES/NO answer format to determine whether the child would benefit from nutrition intervention. The PEACH survey had good sensitivity (88.6%) and specificity (90%). Overall predictive value was 88.6 % (16). However, the PEACH only covered children from birth to 6 years of age and it did not address level of concern, that is whether the parent perceives there is a nutrition-related problem that needs intervention (13).

DEVELOPMENT & VALIDATION OF PNSC TOOL

Develop the construct for measurement and key attributes 12.

For PNSC the construct was defined as parents in the community completing the tool to detect level of nutritional risk for children with special needs from age 1-18 years old. The nutritional risk factors key attributes were set up into three categories (1,4,8,9,11,17,18,19). Questions relating to the three categories form the basis of the screening checklist.

- (a) Health & Special Diets (HS) e.g. underweight or over weight, vomiting, constipation or diarrhea; dental concerns effecting eating; difficulty with special diets, problems with tube feeding.
- (b) Oral Feeding (OF) e.g. oral motor problems, behavioural feeding difficulties; communication.
- (c) Intake (IN) e.g. usage of vitamin/mineral supplements, inadequate or excessive intake of fluids, food or high-energy snacks, intake of non-food items (pica).

Write select & revise items/questions from relevant tools. Consult with content experts & target group 12.

The PEACH tool (16) was chosen as the basis of the initial questions on the Parent Nutrition Screening Checklist (PNSC). Questions were reworded to improve readability and new questions were added to total 30, covering ages 1 to 18 years. The format of YES/NO was still used and a ranking for level of concern from 0 to 3 was added. We compared parent's responses to a clinically defined gold standard, i.e. dietitian's nutritional assessment (the dietitians completed the same screening checklist). Seven parents, eleven paediatric dietitians and six other health professionals familiar with the nutritional needs of CSN reviewed this version of the PNSC. Questions were revised according to their recommendations and used in the first community pilot.

Pre-test items for readability with subset of target group. Conduct pilot testing of screening tool and validation 12.

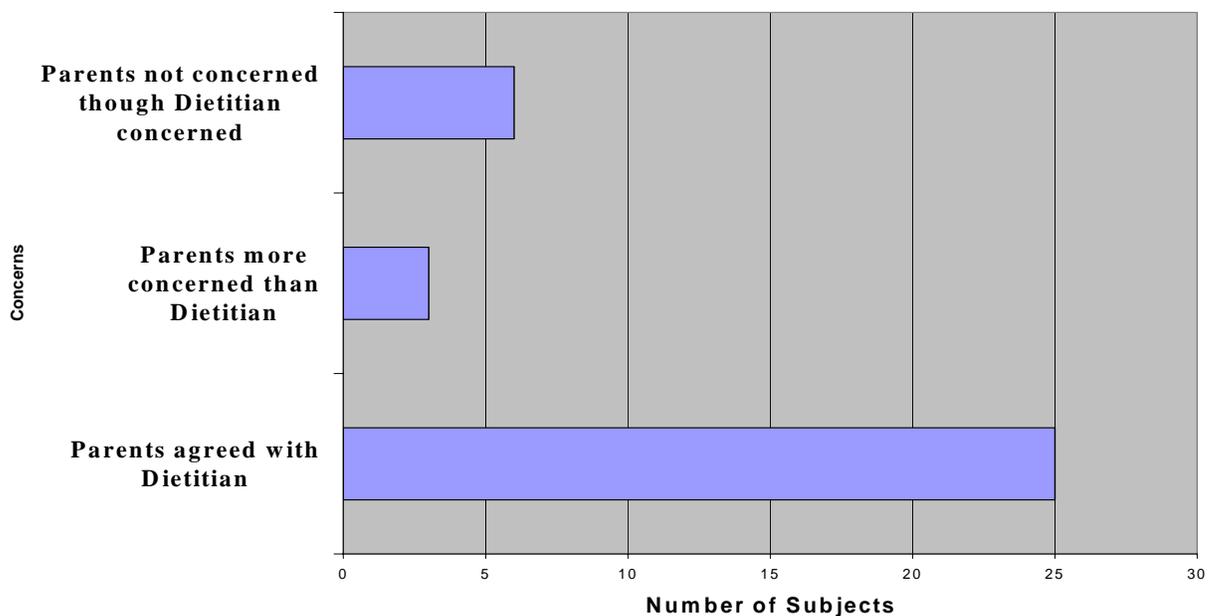
The first community pilot project was funded by BC Health Research Foundation Grant and carried out in the Vancouver BC area in 1997 to assess parent understanding and readability of the PSNC. Fifty-five parents completed the checklist and provided valuable feedback concerning the questions and ranking scale. The questions were revised again and reduced from 30 to a total

of 18. Some of the changes included combining and simplifying questions thus reducing number of detailed questions on specific topics like tube feeding complications and feeding behaviours. The ranking scale was changed from 0 to 3 to 0 to 2, that is 0 = no concern, 1=some concern and 2=very concerned because parents found 0-3 scale confusing with too many levels of concern. Then different parents, paediatric dietitians and other health professionals reviewed the second revision of PNSC.

A second community pilot project funded by Okanagan Similkameen Health Region (OSHR) & Sunny Hill Foundation Primary Investigator award was conducted in 2001 to validate the revised tool using sample size of 34 CSN (20). Parents completed the PNSC and added comments about readability. Using the same sample the PNSC was validated against gold standard of a dietitian’s assessment of nutritional risk based on medical history, weight history, anthropometric measures using SHAPES (21) diet history and computerized nutrient analysis of intake. Dietitians were blind to participants PNSC scores and they completed the checklist with the same questions to be used for comparison.

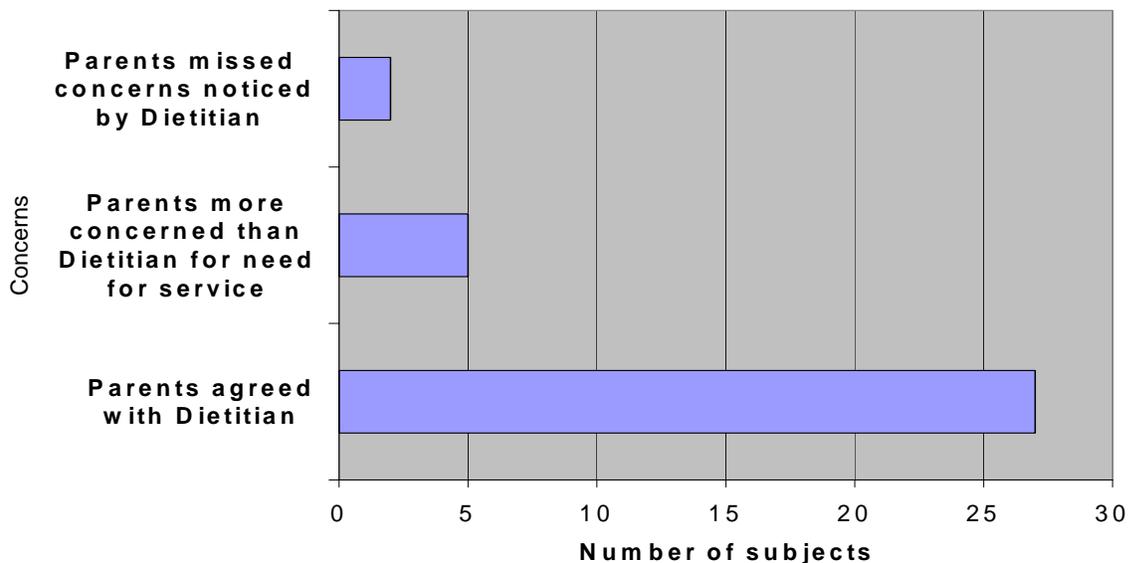
To determine if the checklist is a valid tool we compared the checklists completed by the dietitian and parent. Overall, parents showed a higher level of concern than dietitians which might suggest that the checklist when completed by the parent does not accurately reflect the need for intervention. However, more detailed analysis revealed that there was general agreement between parents and dietitians. To show the reliability and validity of the questions the parent and dietitian responses to the questions were compared. For 25 (73%) out of 34 subjects, dietitians agreed with the parents that they had or did not have nutritional concerns. For 3 subjects (9%) the parents were more concerned than the dietitian, but in these cases, families would probably still need intervention to address the parent concerns. For 6 subjects (18%) the parents were not concerned although the dietitian had concerns. (See Figure 1.) The sensitivity was 83.3 % and specificity was 62.5 % with predictive value positive of 71.4 % for the comparison of questions.

Figure 1 - Parents & Dietitian Comparison for Nutritional Concerns



To determine whether appropriate children would have received nutrition intervention, a scoring system was developed using the results for level of concern (12,16). We determined that a child would need nutritional intervention if they met the criteria of having a total score for level of concern >5 or a score of 2 for one of the three highest nutritional risk questions (covering weight, special diets or tube feeds). Based on this analysis there was agreement between dietitians and parents for 27 subjects (70%) regarding whether the child needed or didn't need nutrition intervention. For 5 subjects (15%) the child did not need service but would have received service because parents indicated levels of concern, which met the criteria. These children and families would probably still need some intervention to address the parent's concerns. For 2 (5.9 %) of subjects the parents missed the concerns recorded by the dietitian so these children needed but would not of received service. (See *figure 2.*) Although this is upsetting, if the tool was used on an annual basis these problems might be picked up at a later date. The sensitivity of the PNSC in this analysis was 82.8 % and specificity was 60 % with predictive value positive of 92.3 % for the comparison of need for intervention.

Figure 2 - Parents and Dietitian Comparison for Need for Nutrition Service



The PNSC can also be used to screen for common areas of concern to aid in the development of educational resources. In the Okanagan pilot project parents had the greatest concern for questions pertaining to food intake, bowel movements and eating behaviours.

Test-Retest reliability 12.

Parents completed the PNSC twice but since the second response was after the dietitian's visit, it was not appropriate to assess test-retest reliability but it was used to evaluate the effectiveness of the nutrition intervention (20).

RELEVANCE TO PRACTICE

This article describes the development, validation and reliability of a new tool, the Parent Nutrition Screening Checklist for Children with Special Needs (PNSC) covering children aged 1 to 18 years, in the community setting. The PNSC has the potential for multiple uses such as: to determine which child needs and which child does not need nutritional intervention, to monitor a child's nutritional needs over time or as they grow and age, to determine the prevalence of nutritional problems and aid in development of appropriate nutrition educational resources and to help plan appropriate services for children with special needs and their families. We would like to work with other dietitians to conduct further testing in the community, clinics and hospital settings.

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APPENDIX 1

Sample Questions from tool --- PARENT NUTRITION SCREENING CHECKLIST FOR CHILDREN WITH SPECIAL NEEDS

Instructions:

Children with special needs often have nutritional concerns. This checklist can help identify those children that could benefit from nutritional support. Please circle YES or NO for each statement and then rate your level of concern by circling the appropriate number: 0 = no concern, 1= some concern, 2= very concerned.

ITEM	YES	NO	LEVEL OF CONCERN
3. My child has problems with bowel movements (e.g. too watery or constipated)	YES	NO	0 1 2
6. My child is on a tube feeding.	YES	NO	0 1 2
8. My child usually: refuses to eat ____ eats too much _____	YES	NO	0 1 2
13. Over a one week period consider: My child eats too much or not enough fruit (includes fruit juices).	YES	NO	0 1 2

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