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Toward a Measure of Communicative Participation for Children with Developmental Speech Disorders

Meghan Darling-White, B.S., M.S., Ph.D.¹

ABSTRACT

The general lack of assessment tools that adequately measure communicative participation has been well documented in the adult literature. However, there has been no systematic attempt to document the availability of these assessment tools in pediatric populations. The purpose of this literature review was to investigate the availability of patient-reported outcome (PRO) tools that measure communicative participation in children. Results indicate that there are no such tools that measure communicative participation in children at this time. In an effort to inspire researchers to develop these tools, the following guidelines for the development of pediatric PRO tools are discussed: (1) consider age-based criteria for tool development and administration, (2) design and format the tool specifically for the target age group, (3) establish content validity, (4) determine whether a parent proxy-report tool is necessary, and (5) consider cross-cultural issues.

KEYWORDS: Communicative participation, children, patientreported outcomes, review

Learning Outcomes: As a result of this activity, the reader will be able to (1) summarize the reasons why patient-reported outcome tools developed for adult populations should not be used for pediatric populations; (2) discuss the availability of patient-reported outcome tools that measure communicative participation in children; and (3) discuss the guidelines that should be implemented during the development of pediatric patient-reported outcome tool development.

It has long been recognized by health care professionals that the presence of a diagnosis or disability does not predict the needs, abilities, or

potential for success of an individual. In an attempt to integrate this knowledge with clinical practices, the World Health Organization

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proposed the International Classification of Functioning, Disability, and Health (ICF).¹ With three basic levels, "body functions and structures," "activities," and "participation," the ICF provides a standard language for the description of a person's functioning and disability in relation to his or her health condition and contextual factors.¹ The body functions and structures level involves functions specific to the anatomy and physiology of the body; the activities level refers to the execution of a task or action; and participation is defined as involvement in a life situation.

By adopting the ICF as the framework for assessment and intervention,² the American Speech-Language-Hearing Association has emphasized the need for our clinical services to address each aspect of an individual's functioning and not just the underlying impairment. As a result, the construct of communicative participation, defined as taking part in life situations in which knowledge, information, ideas, or feelings are exchanged,³ has become increasingly popular in the field of speech-language pathology. Despite the recognition that increased communicative participation is the ultimate goal of speech and language intervention, assessment and treatment most often focus on the level of body functions and structures and activities.4-9 Many have suggested that one of the barriers to the implementation of participation-focused intervention is the lack of assessment tools designed to measure communicative participation.³⁻⁹ A review of patient-reported outcome tools designed to assess communication in adults found that although many of the available instruments had single items related to communicative participation, none of the instruments exclusively measured the construct.³ Although there has been some recent progress in this area, namely with the development of the Communicative Participation Item Bank (CPIB),¹⁰⁻¹² instrument development has been focused on adults with acquired speech disorders. Although there are no published data regarding the differential impact of acquired versus developmental speech disorders on communicative participation,¹⁰ there are several reasons to support the development of a separate assessment tool for pediatric populations.

First, children participate in fundamentally different life situations than adults. A primary

tenet of the measurement of communicative participation is the emphasis that any tool must encompass a multitude of life situations. For adults, this might include personal and household management, leisure, learning, employment, relationships, and community life.^{3,12} Thus, any tool that measures communicative participation in children must include the variety of social situations common for children including classroom activity and play.

Second, measures of communicative participation for adults with acquired speech disorders are predicated on the idea that these individuals have suffered a "loss" of "typical" functioning and can compare their current level of functioning to their former level of functioning. However, children with developmental speech disorders have not suffered such a "loss" because they have developed speech using an atypical speech production system. This difference in conceptual framework must be taken into account when developing candidate items for any measurement tool to be utilized with children with developmental speech disorders. For example, during the development of the CPIB, it was discovered that asking adults with acquired speech disorders to rate their level of satisfaction with their communicative participation was not a good response format because all individuals were generally unsatisfied with their new communication style.¹² However, this may be an appropriate response format for children with developmental speech disorders because it cannot be assumed that this population is generally unsatisfied with their ability to communicate in social situations given the fact that life with a speech disorder is the norm for this population.

Third, due to differences in cognitivelinguistic development between children and adults, adaptations, such as age-appropriate language, are necessary for a tool designed for children. Communicative participation is often measured using patient-reported outcome (PRO) tools because only the patient experiences the physical, environmental, and personal factors that shape success or failure in the wide variety of social situations surveyed.¹⁰ PRO tools measure any aspect of a patient's health status that is provided by the patient without interpretation by another person.¹³ Historically, it was believed that children were not reliable self-reporters due to a lack of cognitive development necessary to understand their own disability. However, children as young as 5 years of age can reliably report on their health status and/or disability given appropriate support.^{14,15} Although general agreement between child self-report and parent proxy-report is often observed, these groups tend to have less agreement for nonobservable functions. Specifically, children provide lower ratings for functions, such as mental health and emotional or social health-related quality of life.^{16,17} Given that many aspects of communicative participation are nonobservable to parents and/or clinicians, children provide a valuable perspective that must be taken into account. Therefore, any PRO tool that measures communicative participation in pediatric populations must utilize the supports necessary (e.g., age-appropriate language) to facilitate accurate self-reporting from children.

It is clear that PRO tools measuring communicative participation in adults with acquired speech disorders should not be utilized for children with developmental speech disorders. The purpose of this literature review was to investigate the availability of PRO tools that measure the construct of communicative participation in pediatric populations.

IDENTIFICATION OF ASSESSMENT TOOLS

An electronic search of the databases CI-NAHL, Medline, and PsycINFO was conducted, using the following search terms: "communication disorders," "speech disorders," "dysarthria," "scales," "instruments," "questionnaire," "measurement," "quality of life," and "participation." The search results were then narrowed by age range to include only those studies that discussed children between the ages of 6 and 18 years of age. In addition, the journals Developmental Medicine and Child Neurology; American Journal of Speech-Language Pathology; Language, Speech, and Hearing Services in Schools; and Journal of Speech, Language, and Hearing Sciences were individually searched using the term "communicative participation." After duplicate entries were deleted from the

search results, the research team (undergraduate researcher assistants and the author) searched each article and compiled a list of all the assessment tools that were mentioned. Interview assessments were not considered because they do not produce a quantitative score with which to compare pre- and postintervention outcomes. The research team wrote a summary about each tool that included the criteria discussed later. The author then determined whether the tool was relevant or irrelevant to the purpose of this review. The research team sought to collect a copy of the original tool whenever possible. This allowed the author to determine if the tool contained items related to communicative participation, regardless of whether that term was utilized in the tool's description. Although several tools were originally developed in languages other than English, these tools were considered for inclusion based on the criteria below as long as there were data to support the use of an English-language translation.

Several inclusive criteria were used in an attempt to identify tools for measuring communicative participation in children. By definition, a PRO tool must include a self-report (completed by the child) form. PRO tools that included a supplemental proxy-report (completed by the parent or clinician) form were considered for inclusion as long as the primary method of assessment was child self-report. Only PRO tools developed specifically for use with children were considered for inclusion. The PRO tool did not have to be developed for a specific disease population or condition (e.g., speech disorders) to be considered. As a final step, the description of the PRO tool's intended use was compared with the definition of communicative participation being utilized in this study. If it was determined that the PRO tool was designed for children and was intended for the assessment of communicative participation, it was included for review.

RESULTS AND DISCUSSION

As a first step toward the development of a PRO tool to assess communicative participation in children with developmental speech disorders, this study sought to review the

available literature in an effort to identify PRO tools currently being utilized for this purpose. After examining over 250 assessment tools, it was determined that there are currently no PRO tools designed to assess communicative participation in children. The PRO tools that came closest to fitting all of the inclusion criteria were health-related quality of life measures, such as the Pediatric Quality of Life Inventory.^{18,19} Although communicative participation is likely an important component of quality of life, the quality of life construct is multidimensional and encompasses all aspects of a person's functioning rather than just communication.⁴ Health-related quality of life PRO tools typically include only a handful of questions specifically related to communication, many of which assess the activities domain rather than the participation domain of the ICF framework. Not surprisingly, previous research has demonstrated only weak to moderate relationships between these two constructs.^{11,20} Therefore, health-related quality of life tools are not adequate assessment tools for communicative participation.

Though disappointing, these results were not unexpected. Although this is the first study to identify the lack of adequate measurement tools for communicative participation in children, the phenomenon has been well described in adults.^{3–8} One literature review led directly to the development of the CPIB, a PRO tool that measures communicative participation in adults with acquired speech disorders.¹⁰ Criteria are available to identify minimum standards for design of PRO tools,²¹ but the development of such tools in pediatric populations requires additional considerations.²² The remaining paragraphs will discuss the guidelines for the development of pediatric PRO tools.

Consider Age-Based Criteria for Tool Development and Administration

Given the significant developmental differences observed throughout the course of childhood and adolescence, it has been suggested that pediatric PRO tools be tailored to specific age groups. Based on a review of the literature of the reliability and validity of child self-report measures, four different age groups have been

proposed for PRO tool administration²²: less than 5 years old, 5 to 7 years old, 8 to 11 years old, and 12 to 18 years old. There is no clear evidence that children less than 5 years old can provide reliable and valid self-report of their health status and/or disability,²³ but with each subsequent age group the likelihood of reliable and valid self-report improves. Although these proposed age groups are based on empirical evidence, they should serve as a starting point rather than strict guidelines. For a tool that measures participation in situations involving communication, the situations may vary in important ways across age groups. Thus, PRO tools should develop individual age cutoffs based on the construct being assessed, the format of the tool, and the population of interest.²²

Design and Format the Tool Specifically for the Target Age Group

To ensure reliable and accurate self-reporting, the design and format of pediatric PRO tools must be tailored to the specific age range and population in question. This can be done in several different ways, including choosing ageappropriate language, response scales, and recall periods (e.g., time over which symptoms are to be reported).²² One way to increase the likelihood that the design and formatting choices are appropriate for the target age group is to assess tool function during focus groups and/or cognitive interviews.²⁴ During the development of an item bank for the Patient Reported Outcomes Measurement Information System (PROMIS) pediatrics group, cognitive interviews with children and adolescents from 8 to 17 years of age led to the identification of issues with the general formatting (e.g., words were too small to read easily), instructions (e.g., too long, young children had trouble understanding the words questionnaire or accurate), certain words or phrases (e.g., words such as irritable, stressed, and how severe were deemed confusing), and item tense (e.g., past tense was preferred over present tense).²⁵ Areas of strength in the PROMIS pediatric group item back included the choice of a 5-point Likert response scale and a 7-day recall period, with even the youngest children (8 years old) demonstrating no

difficulty with these tasks.²⁵ Cognitive interview methodology is useful not only for identifying areas of strength or weakness of an assessment tool, but also for identifying potential solutions as children are often able to provide suggestions for alternative wording or formatting.^{15,25,26}

Tool administration and the range of acceptable response modes are yet another set of items that must be considered when designing and formatting pediatric PRO tools to ensure reliable and accurate self-reporting. Even if substantial effort is made to design and format a PRO tool to a specific age range, there is still considerable developmental variation within each age range that will require alterations to the administration protocol. This is particularly true for children with developmental speech disorders. Conditions that result in developmental speech disorders (e.g., cerebral palsy) often result in co-occurring cognitive-linguistic impairment, which may lead to difficulty in independent test administration. For younger children or children with cognitive-linguistic impairment, it may be necessary to have a parent or clinician read the instructions and individual test items to the child.²² Another area of concern specific to children with developmental speech disorders is the ability to provide verbal responses. Some children may be highly unintelligible or nonverbal making verbal responses inefficient or unavailable. Thus, PRO tools developed for children with developmental speech disorders must include options for responding via multiple modes of communication (e.g., nodding, pointing, written).

Establish Content Validity

In addition to ensuring proper design and format of PRO tools, researchers must ensure content validity of the tool. Content validity, or the extent to which a tool measures the important aspects of the intended construct,²⁷ is primarily established via qualitative research methods like focus groups and cognitive interviews.²² The first step in establishing content validity is identification of the construct that ensures that each potential item of the tool is created within the framework of the construct.²⁸ For the construct of communicative participation, the CPIB focuses on speech communication as opposed to other modalities (e.g., reading, writing, sign language) across various life situations (e.g., home, leisure, work), communication contexts (e.g., face-toface, over the phone, groups), and communication goals (e.g., to schedule an appointment or give instructions).¹¹ Once the construct has been fully defined, focus groups are employed to generate a potential item bank.²⁸ Children have demonstrated the ability to generate items that neither their parents nor their clinicians were able to generate.¹⁵ This will be particularly useful for the construct of communicative participation given the wide variety of communication situations and partners that children encounter on a day-to-day basis. Following the generation of the initial item bank, cognitive interviews can be conducted to determine each item's relevance, clarity, and comprehensiveness.²⁹ These steps should include children from each target population and age range of the PRO tool to ensure content validity across multiple groups.

Determining the need for a parent proxyreport form is another necessary step in the development of pediatric PRO tools. Although child self-report should be considered the standard for participation measures, there will be instances in which children are too young and/ or too cognitively impaired to provide reliable and valid self-reports. In these instances, parent proxy-reports are the only window into the participation construct and are considered a relatively accurate representation of the child's participation status. Parent proxy-report may also be collected in addition to child self-report to gain multiple perspectives of the child's participation status. This may allow clinicians to target goals that meet both the child's and the parent's needs. To provide meaningful comparisons between parent and child perspectives, parent and child report forms should measure the same construct and contain parallel items.³⁰

Consider Cross-Cultural Issues

Finally, it is important to consider cross-cultural issues when developing pediatric PRO tools. The impact of a disability on communicative participation may vary depending on the communication situation and partner, which are often specific to the particular culture of the child. There are also cultural differences surrounding the degree to which a child is considered an agent in his or her own health care. This cultural value will impact the type of information that is shared with a child about his or her own health status, which could impact a child's view of the own disability.²² Reading ability may also vary greatly depending on the educational system of a particular area. Thus, pediatric PRO tools must be validated across a variety of cultures to adequately ensure that the design, format, and content validity of the PRO tool are appropriate for widespread use.

SUMMARY

Although increased communicative participation is often recognized by SLPs as the ultimate goal of intervention,⁴ there are currently no published PRO tools that measure communicative participation in pediatric populations. Development of a pediatric PRO tool for communicative participation will allow children to be active participants in goalsetting and clinicians to better assess treatment effectiveness. In hopes that this review article will inspire the development of such a tool, the following guidelines for the development of pediatric PRO tools were discussed: (1) consider age-based criteria for tool development and administration, (2) design and format the tool specifically for the target age group, (3) establish content validity, (4) determine whether a parent proxy-report tool is necessary, and (5) consider cross-cultural issues.²² A common theme across these guidelines is the need to include the variety of ages and populations that each PRO tool is designed to assess during all phases of tool development. Involvement of these groups is often done via focus groups and cognitive interviews. Thus, if the target population of a PRO tool is children with developmental speech disorders over the age of 5, then focus groups and cognitive interviews must include children with developmental speech disorders from the ages of 5 to 8 years of age. Although this task may seem daunting, the benefit of a reliable and valid PRO tool for communicative participation in children with developmental speech disorders would be immeasurable.

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The author is a faculty member at the University of Arizona for which she receives a salary. The content is solely the responsibility of the author and does not necessarily represent the official views of the University of Arizona.

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