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Incorporating Patient Perspectives in Speech-Language Pathology Research: Moving Towards Digital Outcome Measurement in Pediatrics

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Abstract

The Focus on the Outcomes of Communication Under Six (FOCUS) is a parent-report participation-focused outcome measure that can be used with preschoolers with communication impairments. Speech-language pathologists suggest a digital solution as implementation barriers exist when accessing scores that are needed to understand outcomes and make clinical decisions. To date, caregivers' perspectives have not been studied. Fifteen caregivers were engaged for 30-60 minutes in virtual focus groups and individual interviews to understand their experiences completing the FOCUS-34, perceptions of how a digital solution may be helpful, and recommendations to include. Four themes were identified using thematic analysis: caregivers' current experiences and expectations for outcome measurement, the need for support to complete the FOCUS-34, belief a digital solution would improve service experience, and suggested features for a digital solution. These results provide insights into caregivers' perspectives on outcome measurement and will inform efforts to improve the clinical utility of the FOCUS-34.

Key Words: Speech-Language Pathology, Assessment, Outcome Measurement, Health Services, Communicative Participation, Family Engagement, Focus on the Outcomes of Communication Under Six (FOCUS-34)

Lay Summary

The Focus on the Outcomes of Communication Under Six (FOCUS-34) is a validated parent-report outcome measure that captures change in preschoolers’ communicative participation during speech-language therapies. Despite it being co-developed with end users and widely used in reserach, implementation has been difficult in clinical practice. Speech-language pathologists report the existing paper and fillable PDF formats as a key implementation barrier because they limit rapid access to test scores that are needed to understand children’s outcomes. To date, caregivers’ perspectives and needs related to the FOCUS-34 have not been studied. This project aimed to understand caregivers’ experiences completing the FOCUS-34 in its currently available formats, their perceptions of whether and how a digital solution may be helpful for families, and their preferred features and formats for a digital solution. Fifteen caregivers of preschoolers with communication impairments and experience completing the FOCUS-34 participated in virtual synchronous focus group sessions and individual interviews that were conducted using Zoom. Data were coded and analyzed using thematic analysis, and four major themes were identified: (1) caregivers' current experiences with and expectations for outcome measurement, (2) caregivers need support to complete the FOCUS-34, (3) caregivers believe a digital solution would improve their service experience, and (4) caregivers' suggested features, formats, and considerations for a digital FOCUS-34. Overall, caregivers’ perspectives on outcome measurement will inform future efforts to improve the clinical utility of the FOCUS-34 and allow clinicians and caregivers to better interpret how vital early interventions impact children’s communicative health and development.

Co-Authorship Statement

Specific study objectives and research questions were developed by Sachin Kharbanda and Dr. BJ Cunningham. Data collection was completed by Sachin Kharbanda and BJ Cunningham. Data analysis was completed by Sachin Kharbanda, Boshra Bahrami, and BJ Cunningham. All manuscript writing was completed by Sachin Kharbanda with revisions, suggestions, and feedback from Dr. BJ Cunningham (all chapters). Advisory committee members (Dr. Janis Oram Cardy, Dr. Sheila Moodie, and Dr. Danielle Glista) provided guidance and feedback on the design, analysis, and interpretation of the thesis, as well as feedback on various components of the thesis.

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Chapter 1 - Introduction

1.1 Background and Project Overview

This thesis aimed to inform the development of a digital solution for an existing pediatric participation-focused outcome measure called the Focus on the Outcomes of Communication Under Six (FOCUS; Thomas-Stonell et al., 2010). The study engaged caregivers of preschoolers with communication disorders in focus groups and individual interviews to understand their experiences completing the FOCUS in its current paper format, their assessment needs, and perceived barriers to using a digital solution, as well as their recommendations for features to include in a digital solution. The project identified important caregiver perspectives regarding outcome measurement, and findings will be integrated into a forthcoming digital solution so it will meet caregivers' needs. A digital solution is expected to improve caregivers' experiences with outcome measurement by allowing for automatic and immediate scoring to let caregivers discuss results and make decisions together with their child's speech-language pathologist (SLP). Although this thesis is focused solely on caregivers, a digital solution is also expected to significantly benefit other end users including clinicians, programs, and policymakers.

1.2 Introduction to Outcome Measures and the FOCUS

Outcome measures are used in pediatric rehabilitation to collect data that informs clinical decisions, recommendations, and discussions (King et al., 2011). These measures are useful as they document individual performance in relation to a child's specific set of skills, and can be used to evaluate change over time (Montgomery et al., 1987; Rosenbaum, 2015). By documenting a child's progress, outcome measures can also help families and clinicians make collaborative decisions about goal setting and intervention (King et al., 2011).

The FOCUS is a validated, criterion-referenced, and participation focused outcome measurement tool. It was designed to capture change in preschoolers' communicative participation during speech and language therapy, which means it allows clinicians to measure functional changes in how children use communication to participate in everyday life (Thomas-Stonell et al., 2010). The FOCUS is a parent-report measure that is intended to be administered at the beginning and end of speech and language interventions. It is validated for use with children between the ages of 18 months and 5 years 11 months and can be used with children who have a variety of communication impairments and functional abilities. There are two versions of the FOCUS: the original FOCUS, that has 50 items (FOCUS; Thomas-Stonell et al., 2010) and a new shortened version that has 34 items (FOCUS-34; Oddson et al., 2019). On both measures, FOCUS items are grouped according to children's communicative *capacity* and *performance*. A child's *capacity* is defined as their ability to perform a task in a structured context with supports, whereas a child's *performance* is described as their ability to use communication independently in everyday contexts (Thomas-Stonell et al., 2010).

Items related to *capacity* are grouped into profile scores that assess children's speech, expressive language (e.g., use of specific targets with supports), pragmatics, and receptive language/attention skills; whereas items related to *performance* are grouped into profile scores that assess intelligibility, expressive language (e.g., spontaneous use of targets in conversation), social/play, independence, and coping strategies/emotions (Thomas-Stonell et al., 2010; Oddson et al., 2019). One important feature of the FOCUS it that it was developed with significant input from parents to ensure it assessed outcomes that were relevant and meaningful to them (Cunningham et al., 2020). This dissertation used only the FOCUS-34 as it was the primary outcome measure being used in the clinical program in which the study was conducted.

In clinical practice, the FOCUS-34 can currently be completed in either a paper or fillable PDF format. Parents are asked to rate 34 items that ask about their children's functional communication skills using 7-point Likert scales (Cunningham et al., 2020). Each item is scored from 1 to 7 resulting in a total score that ranges from 34 to 238 points. The main outcome of interest is not the total FOCUS score, but rather the change that is observed between two assessments. A change score of 11 points or more constitutes clinically meaningful change and knowledge about whether meaningful change occurred can be used in combination with other assessment data to inform clinical decisions (Thomas-Stonell et al., 2013; Oddson et al., 2019). The criterion for clinically meaningful change was derived from data collected in a study that utilized the FOCUS to compare communicative participation outcomes for children with speech impairments, children language impairments, and children with both speech and language impairments (Thomas-Stonell et al., 2013). As part of this study, parent and SLP perspectives were collected to determine the change score at which both parents and speech-language pathologists (SLPs) felt children had made meaningful clinical change (Thomas-Stonell et al., 2013). More specifically, parents and SLPs were asked to describe and explain observed changes and why they were important, and from this, the criterion for clinically meaningful change was established (Thomas-Stonell et al., 2013). The criterion of 11 or more points on the FOCUS-34 was determined statistically when the tool was shortened (Oddson et al., 2019).

In addition to change scores, FOCUS-34 profile scores can be used to gather additional clinical information to support goal setting and treatment planning. For example, profile scores may show whether change occurred within capacity or performance, and whether change happened across all profile categories or only in specific areas (Oddson et al., 2019). Clinicians are encouraged to rank order profile scores to better understand a child's change profile (Oddson et al., 2019).

1.3 Communicative Participation in Pediatric Speech Language Pathology

Recent literature states that there are many outcome measures that can be used to assess changes related to children's communication impairments, however, participation-focused outcome measures are lacking (Cunningham et al., 2017). While impairment-focused tools provide data related to changes in specific speech or language skills, they tell nothing about whether communication is changing in everyday contexts. It is important to measure participation focused outcomes in pediatric speech-language pathology for two reasons. First, studies indicate that families are most interested in understanding how services impact children's everyday lives and value these holistic ideas over more traditional outcomes (Lindsay et al., 2004; Roulstone et al., 2013). This is significant as social participation has been noted to positively influence learning, health and well-being, independence, and inclusion (Guichard et al., 2019). Second, participation-focused outcome measures can be used to capture meaningful change for children at all levels of impairment and with all types of communication disorders (Thomas-Stonell et al., 2016). Research indicates children with physical disabilities and complex communication needs experience more participation restrictions than their peers with fewer limitations, which further necessitates the use of outcome measures to accurately assess changes in this important area (Raghavendra et al., 2011).

The FOCUS was developed within the World Health Organization's International Classification of Functioning, Disability and Health (ICF) framework, takes a biopsychosocial approach to conceptualizing a person's health condition, and can be used to think about outcome measurement (World Health Organization, 2001). The framework consists of two parts: (a) Functioning and Disability, and (b) Contextual Factors. The Functioning and Disability section includes three multi-dimensional components (World Health Organization, 2001). *Body Functions and Structures* refers to a person's anatomy and physiology; *Activities* refers to how an individual executes a particular task; and *Participation* refers to an individual's involvement in a life situation. The second part of the framework considers contextual factors that can impact an individual's health condition and includes two components. *Personal Factors* considers factors such as an individual's age, gender, and behavioural disposition; and *Environmental Factors* considers factors related to the individual's social environment such as socioeconomic status (World Health Organization, 2001). The FOCUS includes items that address the Activities and Participation components of the ICF framework, and overall is a measure of children's communicative participation (Thomas-Stonell et al., 2010).

In children, communicative participation is defined as "understanding and being understood in a social context, by applying verbal and non-verbal communication skills" (Singer et al., 2020, p. 1793). It is critical that communicative participation outcomes are measured to ensure children's communication is understood holistically, to support a focus on children's functional abilities and overall health, and to help clinicians and families consider the ways in which communication impairments can restrict children’s social and academic engagement (Clarke et al., 2012; Westby, 2007). As evidenced in one systematic review, childhood communication impairments are associated with Activity limitations and Participation restrictions across the lifespan and can impact daily skills such as learning to read and write; focusing attention and thinking; completing academic tasks; communicating and forming relationships; and navigating the logistics of acquiring, keeping and terminating a job (McCormack et al., 2009). Additionally, children with a history of speech and language impairment have been reported to have more social difficulties than their peers without a history of communication difficulties (McCormack et al., 2009).

1.4 The Ontario Preschool Speech and Language Program

One communicative health system that has adopted a participation-focused approach to outcome measurement is the Ontario Preschool Speech and Language (PSL) program. The PSL program is a provincial speech and language service that is funded by the Ontario Ministry of Children, Community and Social Services. The program employs more than 400 speech language pathologists at 29 regional sites, and those clinicians provide services to over 60,000 preschoolers each year (Cunningham et al., 2020). Services are available for children with a wide range of speech, language, and communication needs from birth to school-entry (age 4 or 5 years in Ontario). Families can self-refer to the program or they can be referred by other service providers such as a pediatrician or early childhood educator. Since 2012, SLPs have been collecting participation-focused outcome data using the FOCUS at six-month intervals for children 18 months of age and older (Cunningham et al., 2020). Since 2019, the program has used the shortened FOCUS-34 (Oddson et al., 2019) exclusively.

Despite initial implementation efforts, clinical adoption, and consistency of use of the FOCUS has been challenging. One study by Kwok et al. (2020) aimed to better understand the challenges associated with implementation by engaging PSL program SLPs and clinical managers in a concept mapping study. More specifically, the study aimed to identify strategies for improving the collection and submission of FOCUS data in the PSL program using the Theoretical Domains Framework (TDF; Michie et al, 2005). This framework can be used to identify factors that impact the implementation of evidence-based tools and practices and link them to specific behaviour change techniques that are likely to help address identified barriers (Michie et al, 2005). SLPs and managers reviewed 90 previously identified strategies (Kwok et al, 2022), and sorted them into groups. Data were used to create a concept map which identified categories of implementation barriers including resources, communication, FOCUS administration fidelity, FOCUS administration logistics, FOCUS user-friendliness for parents, and FOCUS comprehensiveness (Kwok et al., 2020). During the sorting task, participants were also presented with potential strategies for addressing implementation barriers and asked to rate each strategy for importance and feasibility using a Likert scale that ranged from 0 = strongly disagree to 5 = strongly agree (Kwok et al., 2020). The strategy rated as most important and feasible by both clinicians and managers was offering a digital solution for the FOCUS, and this was recommended as a way of reducing the burden on SLPs to manually administer and score the test, and to facilitate use of FOCUS data to inform practice (Kwok et al., 2020; 2022).

1.5 Integrating Parent Perspectives through Patient-Oriented Research and Integrated Knowledge Translation

It is important to integrate the perspectives and needs of families in healthcare research so that outputs are meaningful and can be used to build sustainable, accessible, and equitable healthcare services and systems that will work for patients and families (CIHR; Canadian Health Research Institute, 2019). In pediatric speech-language pathology, it is particularly relevant to involve parents and caregivers in the research process because families are the experts on their children and bring important perspectives to inform care (Rosenbaum, 2011). We must therefore integrate families' expertise to ensure research outputs will effectively improve children's health services (Rosenbaum, 2011). Patient-oriented research and integrated knowledge translation are two approaches that can be useful for integrating families' perspectives.

Patient Oriented (PO) research aims to engage and recognize patients, caregivers, and family members as active partners in health research to ensure it is focused on patient-identified priorities and will result in improved patient outcomes (Canadian Institutes of Health Research, 2019). According to the Canadian Institutes of Health Research, the term ‘patients’ can be described as “*an overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends*” (Canadian Institutes of Health Research, 2019, p. 5). This definition is inclusive of any relation who can help provide context for patient experiences, particularly when the patients are children.

Engaging patients in health service design and delivery can improve their experiences, satisfaction, and care, particularly when organizations commit to acting on the recommendations that result from the engagement (Kiran et al., 2020). Health Quality Ontario developed a Patient Partnering Framework that proposes a continuum of ways to involve patients in research that vary based on resources available to the research team (Health Quality Ontario., 2017). The continuum considers both engagement and effort, and identifies four levels, beginning with the first which requires the least engagement and effort for patients. The four levels are: (1) *sharing*, which involves providing easy to understand information, (2) *consulting,* which involves getting feedback on an issue, (3) *involving,* which includes discussion of an issue to explore solutions, and (4) *partnering,* which involves collaborating to address issues and apply solutions (Health Quality Ontario., 2017; Kiran et al., 2020). This study aimed to *involve* caregivers to discuss a known issue and explore solutions that would be meaningful for them.

The ideas behind PO research are *“in direct alignment with the principles of integrated knowledge translation (IKT)*” (Bishop et al., 2018, p. 2), which is a research approach intended to facilitate practice change. Within IKT, researchers foster meaningful connections and partnerships with knowledge users and work collaboratively throughout to identify key priorities, develop research questions and methodologies, interpret findings, and advance the application of results and outputs into practice (Banner et al., 2019). Collaborative work can be done in numerous ways, some of which include consultation, deliberative dialogue, priority setting, joint research, working groups, and meetings (Gagliardi et al., 2015). This type of collaboration is important as it incorporates the experiential knowledge of those that are impacted by research to foster more democratic, authentic, and transparent health outcomes from the research process (Banner et al., 2019). Successful implementation of IKT can improve the relevance, uptake, and quality of research, and it is recommended that researchers use an explicit framework or strategy to support their IKT efforts (Gagliardi et al., 2015). This study considered a practical stepwise IKT strategy proposed by Liddy and colleagues in 2018 that includes five key activities: (1) *identifying enablers and barriers* to inform aspects that might positively or negatively impact research efforts, (2) *engaging partners* by maintaining active and continuous collaboration between researchers and knowledge users such as policymakers, healthcare providers, and patients, (3) *including patient voice*s to ensure they are involved as collaborators, (4) *co-design and planning* to design, develop and establish strategies for engagement, and (5) *solution-based approaches* to address and solve a particular issue (Liddy et al., 2018). This step-by-step approach integrates ideas from foundational work in iKT by Graham and colleagues (2006), who proposed the knowledge to action (K2A) framework as a tool for supporting the translation of research into healthcare. The first two stages of Liddy et al.'s IKT strategy parallel the first few stages of the action cycle in Graham et al.'s 2006 K2A framework, and were addressed in previous research related to the FOCUS (Cunningham & Oram Cardy, 2020; Kwok et al., 2020; 2022) and through an ongoing partnership with the Ontario PSL program. This project aimed to address stages 3-5 by integrating patients' voices in the research to begin the process of designing a digital version of the FOCUS-34 that would be solution-focused and address known implementation barriers. The integration of patient voices is critical for ensuring research outputs reflect patients' lived experiences and will improve their quality of care (Liddy et al., 2018).

IKT and patient engagement processes like patient-oriented research provide a vehicle for ensuring research addresses health disparities and improves the delivery of effective and responsive healthcare services (Banner et al., 2019). Incorporating parent and caregiver perspectives through

IKT provides space for expertise external to ‘traditional’ sources such as the research literature or researchers who are considered experts in a particular topic area (Walton et al., 2018). In fact, in pediatrics it has been noted that the key to improving health outcomes in children is to actively engage parents in decision making (Walton et al., 2018), which can include engaging them in research related to their children’s health.

1.6 Problem Statement and Study Rationale

Previous research has identified barriers associated with SLPs’ perceptions regarding the collection, submission, and clinical use of FOCUS data (Kwok et al., 2020; 2022). To date, no research has investigated caregivers’ experiences, needs, and preferences related to outcome measurement using the FOCUS-34. This study therefore engaged caregivers of preschoolers with speech, language and communication needs to understand their experiences with and needs for outcome measurement in the PSL program. The FOCUS-34 was used rather than the original 50-item FOCUS as it was the primary outcome measure used in the PSL program at the time of this study.

1.7 Research Aim and Question

This project engaged caregivers’ in virtual focus groups and individual interviews to understand their experiences completing the FOCUS-34 in its currently available formats (paper, fillable PDF), their perceptions of whether and how a digital solution may be helpful for families, and their preferred features and formats for a digital solution. To do this, three research questions were investigated: (1) What are caregivers’ experiences completing the FOCUS-34 in its current formats? (2) Would caregivers find a digital solution for the FOCUS-34 helpful? and (3) What features/formats do caregivers view as important for a digital solution for the FOCUS-34?

Chapter 2 - Methodology

2.1 Ethical Considerations

This study was conducted as part of a quality improvement project requested and supported by the Ontario Ministry of Children, Community and Social Services. As this was a quality improvement initiative, research ethics board review was not obtained. Quality Improvement is described as "systematic, data-guided activities targeting immediate improvements in health care delivery in particular settings" (Stiegler & Tung, 2017, p. 1). Quality improvement projects do not require the same ethical approval as research studies (Hunt et al., 2021), thus quality *considerations* must be incorporated to ensure participants are not at risk of harm during the study. For example, since quality improvement projects do not require patient consent (Stiegler & Tung, 2017), it is important to provide participants autonomy to only disclose information they wish to provide throughout the research process. Considerations for this project included making all preliminary demographic survey questions optional, and not requiring responses to focus group questions. In quality improvement studies it is essential to have confidentiality protections in place to protect participant data and maintain anonymity due to the collaborative nature of focus groups (Reinhardt et al., 2003). For example, there is the potential for privacy breaches with video and audio recording focus groups or individual interviews. To mediate this risk, specific procedures for ensuring confidentiality throughout the research process were developed and shared with participants prior to beginning each focus group and individual interview.

2.2 Participant Recruitment

Fifteen parents and caregivers of preschool children with communication impairments who were receiving speech-language pathology services in Ontario's PSL program were invited to participate in a virtual synchronous focus group by their regional coordinator (local manager) or SLP. Coordinators and SLPs were asked to identify parents or caregivers who were willing to participate in a one-hour virtual focus group to share their experiences with the FOCUS-34. Inclusion criteria were that participants had (1) completed the FOCUS-34 on at least two occasions, and (2) were fluent in conversational English. Interested families were directed to an online survey link where they could enter their contact information and share their preferred day and time for a virtual focus group with the research team. Participants were then contacted via email by a research coordinator to confirm the date and time of their focus group. Coordinators and SLPs attempted to identify participants who were representative of geography (north, south, east, west; urban, rural), race, gender, and socioeconomic status. It was specified that the goal was for participants to also differ by their child's age, type of communication difficulty, and functional communication level, although ultimately the sample was one of convenience.

2.3 Procedures

Most participants were engaged in one virtual focus group session with 1-3 other caregivers, but some participated in an individual interview session. All sessions were conducted synchronously using Zoom videoconferencing software between March and April 2022, and were planned as group-based, but scheduling conflicts meant some sessions were run as individual interviews. Sessions lasted up to 60 minutes and were moderated by the thesis supervisor and co-moderated by the Masters trainee.

Virtual focus groups were selected to attempt to ensure inclusion for families whose participation might otherwise have been limited by time, distance, or social barriers (Abrams & Gaiser, 2017; Tran et al., 2021). The synchronous nature of the focus groups allowed participant interactions to occur in real-time, which facilitated the generation of ideas and allowed participants to gain new insights from dialogue with others (Abrams & Gaiser, 2017). This setting also allowed for the sessions to be securely recorded, auto transcribed, and stored (Tran et al., 2021). Thematic analysis has been noted to be a helpful approach for identifying patterns within and across qualitative data in relation to participants' lived experiences, views and perspectives, and behaviors (Braun et al., 2021). Using this rigorous technique helped strengthen our understanding of the data collected (Braun et al., 2021), and ensured caregiver perspectives were accurately represented.

Prior to participating, caregivers completed an anonymous online survey to report demographic and diversity data (e.g., geography, socioeconomic status, race). The survey was administered using REDCap, a secure data collection server (Harris et al., 2019). A copy of the preliminary demographic survey is presented in Appendix A.

Focus group sessions were structured using an interview guide that was developed to plot the course of the sessions from start to finish (Doody et al., 2013). The interview guide was utilized by the moderator and co-moderator to guide participants through an introduction, familiarization with the group/topic, and five focus group questions with probes (see Appendix B). More specifically, the moderator, co-moderator, and participants introduced themselves, and then the moderator discussed the purpose, ground rules, and confidentiality of the session to foster an inclusive environment. After the introduction, there was a brief description of the intended purpose and function of FOCUS-34 in the Ontario PSL Program to ensure all participants had the same background knowledge. Following this, five interview questions were asked to gauge how caregivers experienced the FOCUS-34, their views on the benefits of a digital solution, and their preferences and recommended considerations for a digital version. Probes were used to elicit responses as necessary (Doody et al., 2013). The moderator concluded the focus group by presenting next steps and thanking participants for their time and contributions (Doody et al., 2013). Participants were compensated with a $40 gift card of their choice. Gift cards were delivered via email.

Focus groups were recorded and auto transcribed using Zoom. Recordings and transcripts were stored in a secure OneDrive folder housed at Western University. To ensure accuracy, the masters trainee reviewed each transcript together with the video recording and corrected any transcription errors or omissions. Transcripts were then anonymized to ensure participant confidentiality. This process involved replacing participant names with study identification numbers, and replacing all other identifying information (e.g., program names, geographic locations, clinicians' and children's names) with generic descriptors.

2.4 Data Analysis

Quantitative demographic survey data were analyzed descriptively using count and frequency. Qualitative focus group data were coded and analyzed using thematic analysis, a systematic process that involved identifying, analyzing, and reporting themes within the data across five phases, which are described next (Braun et al., 2021; Tran et al., 2021).

(1) **Initial review**. The first phase involved becoming immersed in the data by reviewing transcripts and noting initial observations and personal biases (Braun et al., 2021). Transcripts were printed and reviewed, and initial observational notes were recorded in the margins.

(2) **Coding**. Prior to coding, transcripts were reviewed a second time to generate initial codes that described participants' comments (Braun et al., 2021). Codes are defined as small units of analysis that capture compelling features of the data relevant to the research question (Braun et al., 2021). Coding is a subjective process, shaped by the researcher's interpretation of the data. In thematic analysis, subjectivity is viewed as a *strength* and is not a source of bias (Braun et al., 2021), and researchers are discouraged from attempting to establish reliability of coding as different researchers will notice and make sense of data in different ways based on their individual perspectives and experiences (Braun et al., 2021).

Coding typically involves a single coder, however, to ensure data were interpreted accurately, coding for this study was done collaboratively. More specifically, initial codes were set by the Masters trainee and then reviewed by the supervisor to ensure findings were reflective of the clinical context in the PSL program. Collaborative coding was done for each interview transcript and disagreements were resolved through discussion.

An inductive approach was used during coding so that the dataset could be used as a *“starting point for engaging with meaning by giving voice to participants and incorporating articulated experiences as the preliminary point for coding and theme development”* (Braun et al., 2021, pp. 56). An inductive approach is recommended for researchers wanting to understand participants’ experiences and preferences when there are no prior hypotheses or frameworks in place (Braun et al., 2021). Within the inductive approach, semantic codes were used to describe what was explicitly expressed by participants *“by staying close to their language and the overt meanings of the data”* (Braun et al., 2021, pp. 57). Both an inductive approach and the use of semantic coding aligned with the aim of this study as they allowed participant perspectives to be understood, highlighted, and incorporated. Codes were set after reviewing the data set twice to ensure that evolutions in codes and coding labels were properly captured (Braun et al., 2021).

(3) **Identifying themes**. Once codes were developed, more interpretive analysis of the data occurred as themes originating from the codes were identified. A theme represents a significant pattern that captures something significant related to the research question (Braun et al., 2021). This step involved organizing codes into broader themes that categorized participants’ experiences and preferences. Themes were reviewed and refined to ensure they fit in relation to both the identified codes and the full dataset (Braun et al., 2021). The team also reflected on whether the themes told a convincing and compelling story about the data and began to conceptualize the nature of the themes.

(4) **Defining themes**. The next phase involved defining and naming themes by identifying and describing the ‘essence’ of each theme (Braun et al., 2021). This step involved conducting and writing a detailed analysis of each theme and establishing connections between what each theme represented and the overall data set.

(5) **Reporting results**. The last step was to report results and provide a concise, coherent, and logical account of the data within and across the identified themes (Braun et al., 2021).

Thematic analysis has been noted to be a helpful approach for identifying patterns within and across data in relation to participants' lived experiences, views and perspectives, and behaviors (Braun et al., 2021). Using this rigorous inquiry technique helped strengthen researchers' understanding of the data collected so that caregiver perspectives were accurately represented (Braun et al., 2021).

2.5 Positionality of the Researchers

My positionality as a researcher was underpinned by a critical theorist lens which inevitably influenced the research process. Critical theory recognizes a reality shaped by ethnic, cultural, gender, social, and political values that are mediated by power relations that are socially and historically construed (Ponterotto, 2005). By recognizing my position as a racialized male that was neither a caregiver nor SLP, I adopted an outsider perspective which allowed me to interact with the data differently than someone coming from another position, as I had few pre-conceived notions about participants' experiences.

While it is acknowledged that a critical theorist perspective may have influenced this work, it should be noted that no specific critical theory paradigm was explicitly used to inform the project. Thematic analysis was used as the method rather than a specific paradigm to avoid the incorporation of epistemological and ontological perspectives, which can result in theoretical perspectives dominating the focus of the research (Maguire et al., 2017; Ponterotto, 2005; Smith et al., 2011). Thus, avoiding the use of a paradigm such as critical theory allowed us to stay close to the research questions and data to accurately describe participants' experiences (Smith et al., 2011).

Given there was intent to develop a digital solution when designing the study, researchers' motivations likely influenced decision making surrounding this study's methodology and the development of the interview guide. The research team recognized that previously collected data supported the idea there was a need for a digital solution and that this knowledge guided the research process and procedures. Thus, focus group questions were worded broadly to avoid incorporating additional hypothesized beliefs about the specific formats or features for a digital solution that may be preferred by caregivers' perspectives.

2.6 Reflexivity

Reflexivity is a process that involves acknowledging the role and biases of the researcher in the research process to promote rigor and transparency throughout the project (Cruz & Higginbottom, 2013). As subjectivity is considered a *resource* in qualitative research, reflexivity is used to situate the research in the context of the study environment and researcher practices, and acknowledges that analysis happens at the intersection of the dataset, within the context of the research environment, and according to researchers' skills and perspectives (Braun et al., 2021). Given the interactions between the researchers and participants in this project, it was important that the researchers engage in reflexivity. I, the Masters' trainee, used a reflexive journal across all phases of this research (i.e., following each focus group, at initial transcript review, throughout the coding and analysis process, when identifying and defining themes, during writing). For example, creating reflexive notes before the focus groups allowed me to first recognize how my background and roles in society could impact my decision making and the way I interacted with the data. Additionally, using reflexive notes during data collection allowed for more transparency and clarity during the generation of codes. During data analysis, using reflexivity allowed me to stay in touch with my positionality as I could explain to my research team why I chose to code things in certain ways. This helped me be flexible with interpreting the data in different ways, allowing me to understand the specific features caregivers' valued in a digital solution, but also the unique ways in which administration of the FOCUS-34 could be improved more generally. The use of reflexive notes was particularly important when I experienced feelings of uncertainty about caregivers' perspectives, which was sometimes difficult because I was not a caregiver myself.

Chapter 3 – Results

3.1 Participant Characteristics

Most participants (*n*=14, 93%) identified as female, Caucasian (100%), and educated (*n*=7, 47% had a university certificate or diploma). Most participants had an annual household income over $100,000 (*n*=14, 93%), lived in a smaller community (*n*=7, 47%), and were located in southwestern Ontario (*n*=9, 60%). More information regarding participant demographics is presented in Table 1.

Table 1.

Focus Group Participant Characteristics.

Variable		N	%
Gender			
	Female	14	93%
	Male	1	7%
Ethnicity			
	Caucasian	15	100%
Education			
	College or other non-university	4	27%
	University degree or diploma	7	47%
	Post-graduate degree	4	27%
Family Income			
	$80,000 to $99,999	1	7%
	More than $100,000	14	93%
Community Size			
	Large Urban	6	40%
	Medium Population	2	13%
	Small Population	7	47%
Geographic Region			
	Northern	5	33%
	Southwestern	9	60%
	No Answer	1	7%

Most participants' children (*n*=12, 80%) identified as male, and the majority (*n=6,* 40%), were aged 37-48 months, and were described by their caregivers as having speech challenges (*n=11,* 73%). More information regarding demographic information for participant's children is presented in Table 2.

Table 2.

Demographic Characteristics of Participants' Children.

Variable		**N**	**%**
Gender of Child (by parent report)			
	Female	3	20%
	Male	12	80%
Child's Age (in months)			
	< 12	1	7%
	13 – 24	1	7%
	25 – 36	2	13%
	37 – 48	6	40%
	49 – 60	5	33%
Child's Communication Challenges (as described by parents)			
	Speech	11	73%
	Stuttering	3	20%
	Expressive Communication	2	13%
	Childhood Apraxia of Speech	1	7%
	Non-Verbal	2	13%
	Autism or suspected Autism	3	20%
	Visual Impairment	1	7%
	None	9	60%
	Other	2	13%
Relationship to Child			
	Parent	15	100%

Most participants (*n*=13, 87%) did not receive training to complete the FOCUS-34 and the majority (*n=9*, 60%) did not complete the FOCUS-34 with a SLP. Most participants (*n=8*, 53%) did not have their child's FOCUS-34 scores discussed with them, and most (*n*=8, 53%) did not view the FOCUS-34 as helpful. More information regarding participants' experiences with the FOCUS-34 is presented in Table 3.

Table 3.

Participants' Experiences with the FOCUS-34

Variable		**N**	**%**
Times FOCUS-34 completed*			
	Never	2	13%
	1 – 2 Times	6	40%
	3 – 5 Times	5	33%
	5 >	1	7%
	No Answer	1	7%
Received training to complete the FOCUS-34			

Yes	1	7%
No	13	87%
No Answer	1	7%
Completed FOCUS-34 with a SLP		
Yes	4	27%
No	9	60%
Sometimes	1	7%
Knew why FOCUS-34 was completed		
Yes	7	47%
No	7	47%
No Answer	1	7%
FOCUS-34 scores shared by SLP		
Yes	6	40%
No	8	53%
No Answer	1	7%
Felt the FOCUS-34 was helpful		
Yes	6	40%
No	8	53%
No Answer	1	7%

*A few caregivers (*n*=2, 13%) reported they had never completed the FOCUS-34 on the initial demographic survey. We believe this was because they did not initially recall completing the tool. Prior to focus groups and individual interviews, the FOCUS-34 was presented and reviewed, and all participants confirmed they had knowledge of and experience completing it.

All participants (*n*=15, 100%) had a smartphone. Most (*n=8*, 53%) had above average experience using a computer keyboard and mouse, and average experience using videoconferencing technology (*n=12,* 80%). More information regarding participant’s technology ownership and experience is presented in Table 4.

Table 4.

Technology Ownership and Usage.

Variable	**N**	**%**
Technology Ownership		
Tablet	9	60%
Smart Phone	15	100%
Laptop	10	67%
Desktop Computer	8	53%
Other	0	0%
Experience Using Computer Keyboard and Mouse		
Beginner	0	0%
Average	7	47%
Above Average	8	53%

Experience Using Laptop/Desktop Computer			
	Beginner	0	0%
	Average	6	40%
	Above Average	9	60%
Experience Using Mobile Devices (smartphones/tablets)			
	Beginner	1	7%
	Average	6	40%
	Above Average	8	53%
Experience Using Applications (Apps)			
	Beginner	2	13%
	Average	6	40%
	Above Average	7	47%
Experience Using Videoconferencing Technology			
	Beginner	1	7%
	Average	12	80%
	Above Average	2	13%

3.2 Results of Thematic Analysis

Four major themes associated with caregivers’ experiences with and preferences for completing the FOCUS-34 were identified. Each major theme had associated sub-themes presented in Figure 1. Themes and sub-themes are presented below together with selected quotes that further illustrate caregivers’ experiences and needs related to outcome measurement.

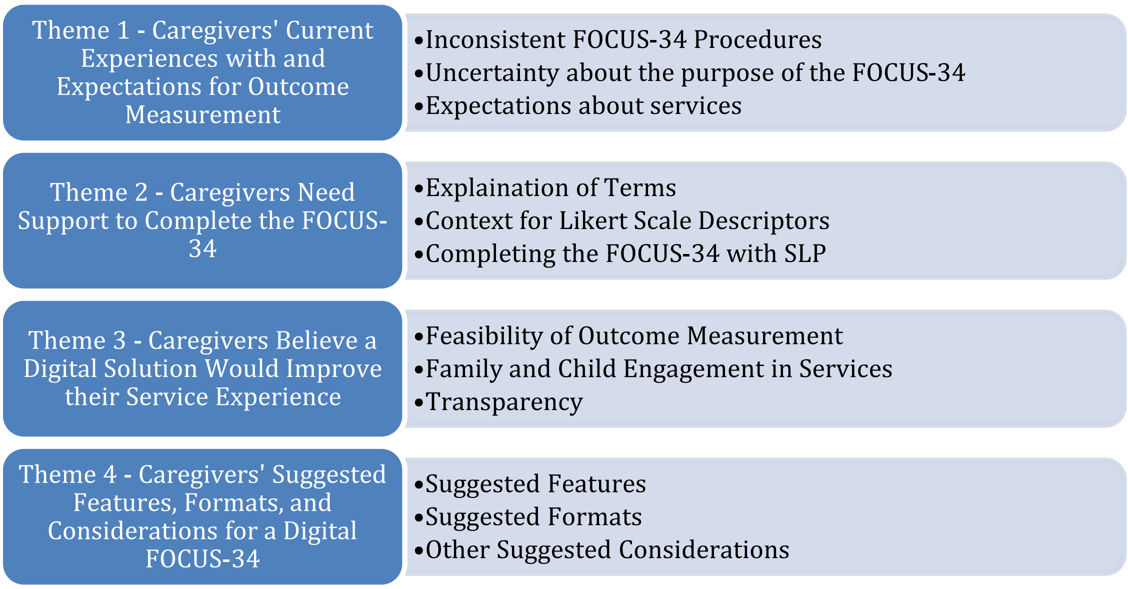

Figure 1. Identified major themes and associated sub-themes

3.2.1 Theme 1 - Caregivers' Current Experiences with and Expectations for Outcome Measurement

The first theme describes caregivers’ expectations for and experiences with outcome measurement using the FOCUS-34 in the Ontario PSL program. Caregivers reported inconsistencies with respect to their experiences with the format, timing, and procedures for completing the FOCUS-34. They also expressed uncertainty regarding the purpose of outcome measurement, particularly because most received no feedback after submitting their FOCUS-34 forms. Caregivers also described a desire to have their perspectives integrated within services and an expectation that outcomes be linked to normative data.

Inconsistent FOCUS-34 Procedures. Caregivers reported having completed the FOCUS-34 in multiple formats (i.e., on paper, as a fillable PDF), and that they typically completed it irregularly and alone without support from their SLP. Many reported being given the questionnaire at their first appointment and being asked to complete it at home and return it to their SLP, but the frequency with which they were asked to do that varied. Examples of reported completion intervals included at the start and end of therapy blocks, every 6 months, at intake and again later once assigned to a SLP, and with two different service providers/in multiple locations. Many participants were not concerned about completing the FOCUS-34 independently, noting it was relatively straightforward and did not take long to complete.

“I feel like it's pretty straightforward to complete” (Participant 016)

“It's not a questionnaire that takes a long time right” (Participant 001)

Uncertainty about the purpose of the FOCUS-34. Although caregivers felt the FOCUS-34 was brief and relatively easy to complete, most reported being given the form by either their SLP or program without explanation, so they did not understand why it was required or how their data would be used.

> *"There wasn't too much explanation about it at all other than what's directly on the form."* (Participant 012)

Similarly, many caregivers reported receiving no follow-up about their responses or their child's scores or progress, which added further confusion about the purpose of outcome measurement. Some participants believed that the FOCUS-34 was part of an onboarding process or a baseline measurement, and some believed their SLP might use the data to inform therapy.

> *"It's kind of like a baseline to determine progress, so I understand where they're kind of getting to it, it's just that it feels like it's just done, and then that's it."*
> (Participant 010)

Although most participants viewed the FOCUS-34 as being insignificant, one caregiver reported they appreciated the tool, noting that it helped them consider the broader dimensions of communication and how their child was using communication to participate.

> *"It did highlight some things that maybe I didn't think about before when it came to communicating with other children playing games. I never really thought about all the little parts of communication, so it kind of put it in perspective. Maybe it's way bigger than I thought it was. It's not just a few sounds here and there, it's all it's all of communication."* (Participant 006)

Some caregivers reported challenges associated with completing the FOCUS-34, and two main issues were identified. First, some caregivers reported experiencing negative emotions when completing the FOCUS-34 for children who were younger or had limited communication skills, as providing low ratings made them feel as if their child was not progressing.

> *"When we were doing it, it was a little bit like almost sad and frustrating, because there were so many ones."* (Participant 014)

Others reported difficulty rating some FOCUS-34 items during the COVID-19 pandemic. Ratings were reported to be particularly difficult for items focused on children's social interaction skills because families were adhering to the recommended restrictions and many children had limited, if any, opportunity to engage in play with peers.

> *"But the other thing is he wasn't out in the community, because of all the restrictions that were imposed so again, it was like, how do we answer this, because he wasn't getting that socialization right."* (Participant 015)

Expectations about services. In addition to describing their experiences completing the FOCUS-34, caregivers shared some expectations regarding the focus of outcome measurement and service delivery, and expectations varied across families. For example, some expected a focus on improving children's participation and social engagement, but the majority expected their SLP to measure and report outcomes relative to normative data that indicated how "behind" their child was.

> *"In my mind what I hope to get from my son being in speech therapy is that he can communicate with his peers and that he can communicate with strangers and feel comfortable doing so and not be embarrassed because he knows that people can't understand what he's saying."* (Participant 003)

> *"Until they're in school I really have no clue what to expect so that would be helpful, just so I know like how far behind his peers would he be on average, just so I know what we're going into when we start school - that he's going to be very behind his peers."* (Participant 005)

3.2.2 Theme 2 - Caregivers Need Support to Complete the FOCUS-34

This theme examines supports caregivers felt would improve their outcome measurement experience. Identified supports included explanations for communication terms used in some FOCUS-34 items, receiving additional context for the FOCUS-34 Likert rating scale descriptors, and being able to complete the measure together with their SLP, which was viewed as particularly important the first time a family was asked to complete the FOCUS-34.

Explanation of Terms. Some caregivers found the terminology used in some FOCUS-34 items confusing or vague, which they felt made them difficult to interpret and rate precisely. Caregivers believed their confusion may be due to them having different background knowledge than their SLP. It was reported to be particularly difficult for caregivers to consider both children's verbal and non-verbal communication skills when rating FOCUS-34 items.

> *"I also do feel like the questions are not specific enough. There's a certain section that talks about how your child is able to communicate and I always have a hard time with that because it doesn't specify if it's specific to gestures, verbal, or whatever, so I found that extremely hard to fill out because I'm like yes, she can communicate she needs something, however, she can't use her words. So do I say yes she can or she can't?"* (Participant 010)

Context for Likert Scale Descriptors. The Likert Scale descriptors were confusing for some caregivers, who struggled to differentiate the response options (e.g., a little like my child vs. somewhat like my child). These caregivers expressed the need for support choosing from the possible response options.

> *"Yeah, so when they say a lot or little or a great deal if you can hold your finger or cursor over, and it could explain to you… This means 50% of the time, your child is doing this."* (Participant 013)

Completing the FOCUS-34 with the SLP. Because of their challenges interpreting some parts of the tool, most participants said they would feel more confident completing the FOCUS-34 together with their SLP because they would be able to ask questions and get explanations for individual items. This was reported to be particularly important the first time they were asked to complete the measure.

> *"I found it more helpful to fill out with the therapist because in the moment, she was able to clarify - okay, it says communication, so they mean gestures, does he do this, and she could kind of give examples, or I could clarify like okay well he does this, does that mean yes or no? So it was more of a conversation."* (Participant 012)

3.2.3 Theme 3 - Caregivers Believe a Digital Solution Would Improve their Service Experience

This theme describes the ways in which a digital solution for the FOCUS-34 would improve caregivers' experiences with outcome measurement. Caregivers believed a digital FOCUS-34 would improve the feasibility of outcome measurement, family and child engagement in services, and transparent communication about data and outcomes.

Feasibility of Outcome Measurement. Caregivers believed it would be easier for them to complete and return a digital measure, and that the option to complete the FOCUS-34 in their home environment would allow them to observe their child naturally, which may let them answer questions more accurately. Caregivers also felt it would be helpful for them to complete the FOCUS-34 online and then discuss results with their SLP.

> *"It's helpful to sit in your own environment where you often see the child and observe the child, and if you have a quiet moment to really think through because it helps me to be able to imagine situations where I see him, and how he responds in those situations."* (Participant 013)

Family and Child Engagement in Services. Increased child and family engagement was identified as a benefit of a digital solution. Several participants felt a digital solution could allow children to become active participants in therapy because they would be able to review data at home with their caregivers (if desired by the family).

> *"I think it would actually be cool to share that with him too, so if it was accessible and something that we could look at, I want him to be involved. I think something like this might be fun to review together and we could try to explain that to him because he's at the age where he is starting to really understand more about the program and everything."* (Participant 005)

Caregivers also felt that being able to see measurable progress would motivate them to continue with therapy and work on recommendations between therapy sessions and blocks. Caregivers noted that being able to see progress would provide them with confidence regarding the work they were doing with their child at home.

> *"Just to have more visual cues just so I can help them, so I know that we're making progress, because it is frustrating sometimes when you go week after week after week and it's like are we getting anywhere? Are we making any gains or are we just going around in circles?"* (Participant 006)

Transparency. Participants identified several ways in which a digital solution would improve transparency between clinicians, programs, and families. Caregivers felt a digital solution could provide families with timely feedback about children's progress, allow families to share information with other caregivers and providers, and ensure a centralized place where families could store and access information.

Caregivers stressed the importance of receiving timely feedback about their child's progress and noted this would reduce frustration and allow them to stay up to date on their child's development. Many noted that being able to receive feedback at home would give them time to process results and formulate appropriate questions to ask when meeting with their SLP, which was reportedly difficult to do when receiving feedback in real time.

> *"I feel like if something was online, we could do it our own time and kind of manage it that way, and then later on that night kind of process the information to make a plan with the information in front of us."* (Participant 002)

Caregivers felt transparency could be further improved with a digital solution that would allow them to share information with other family members, care providers, or educators. A few participants reported that the ability to share knowledge across providers could facilitate communication and collaboration to support children.

> *"Just discussing it with your spouse because I usually attend the sessions. I'm just thinking outside the family a little bit right now, like you know my parents and my in laws are very involved in my son's life and so maybe they would like to see some of the progress that the child has made if they see them on a regular basis, and maybe work with them because they're retired and they have time and they would want to do those things."* (Participant 007)

> *"Also, to [share with the] school and the educators, kind of these are the areas that we're really concentrating on, and this is why it is helpful, The school often asks for different pieces of feedback as they're getting to know the child at the beginning of the school year,*

> *so it'd be helpful to have it right at the drop of a hat to say like yep, these are areas of concentration for him.* (Participant 013)

Finally, participants felt a digital solution could improve transparency and openness to services and the outcome measurement process by consolidating information and providing a centralized place where SLPs and families could both easily access the same information. Caregivers also felt a digital solution would require less paperwork and may reduce their SLP’s workload.

> *“The problem is that we have all these papers everywhere …being able to go - Oh, I can check my App real quick, this is what I'm supposed to do with my daughter - instead of being like here's a whole stack of papers.”* (Participant 010)

> *“I feel like it would be easier for the clinician to discuss the results if they see exactly what I see.”* (Participant 001)

3.2.4 Theme 4 - Caregivers' Suggested Features, Formats, and Considerations for a Digital FOCUS-34

This theme examines caregivers’ suggested features and formats for ensuring a quality user experience with a digital FOCUS-34. Caregivers’ additional suggested considerations for developers are also presented.

Suggested Features. Suggested features were related to the way output should be shared and displayed, how families could communicate with their SLP, required explanations for components of the FOCUS-34, and having a reminder system to ensure timely and accurate completion. More specific details on caregivers’ suggested features are presented next.

i. Show and explain change and profile scores. Caregivers described a desire to see FOCUS-34 total and change scores, as well as change in specific areas of communication (i.e., profile scores) so they could track their child’s progress. For some, this included the desire to track change between individual sessions. Caregivers were also interested in knowing whether changes were meaningful, and what their child’s communication strengths and weakness were.

> *"If there are certain categories where your child has improved by 50 points, and this is significant or insignificant, you know, we need to continue working in this area. So, I think it's just flagging what's the overall score and then in the future, where they are improving and is it meaningful or not."* (Participant 001)

Importantly, caregivers stressed they wanted to receive the same feedback as their SLP, which they felt would facilitate conversation and avoid confusion. When meeting with their SLP, caregivers wanted support to understand change scores, and to identify their child's communication strengths and challenges.

> *"Then the therapist can do their assessment and reconfirm your child's needs based on your score. Say they scored low in Category A, B, or C, so we're going to work on that so in the future, when you fill out these you should see the score increase or decrease."*
> (Participant 001)

To further support caregivers in receiving and interpreting FOCUS-34 scores, participants recommended including guidance on how to interpret scores, an indicator for whether change was significant, and specific explanations of possible reasons for change, no change, or regression. Similarly, caregivers requested an explanation of whether and how expected change may vary based on a child's age or developmental stage.

> *"In the end it gives you a score, so I would just want to know what does that mean? I know there might be a written description, but if you're going to give me a score then tell me what it means."* (Participant 004)

A few participants recommended a feature that would allow caregivers to review previously completed FOCUS-34 forms so they could compare scores and reflect on change.

> *"If the child began therapy on X date, and this was the assessment form at that time, these were the goals of the therapy, and then next page would be like the second time, the third time, and then be able to see over time. Like yes, these were the scores from the assessment, but also this was our focus because of the assessment because these are the areas we are focusing on, and this is what we did about it."*
> (Participant 013)

ii. Varying display options for completing the FOCUS-34. Caregivers suggested offering different display options so families could choose how to view the FOCUS-34 based on their preferences. Suggestions included the option to present FOCUS-34 items one at a time or to have all items presented on the same page, presenting items in categories (nonverbal, verbal) to facilitate families' comprehension about the communication skill they were being asked to rate, and including an option to go back to previous questions.

> *"Questionnaires that have asked my preference at the beginning, like do you want one question at a time, or do you all the questions on the same page?"*
> (Participant 012)
> *"As long as there's a way to easily go back to previous questions because I found that when I was working on subsequent questions, it would clarify previous questions. Like oh that question was actually talking about this, so I have to go back and change question 19 because it was asking something different."* (Participant 012)

iii. Visual Display of Results. Visual displays were recommended (e.g., colourful line graphs depicting change) to help caregivers conceptualize their child's development across total and profile scores. Visual displays of change were viewed as particularly important as participants felt it would make it easier for them to interpret their child's FOCUS-34 results.

> *"Visuals really show you progress and differences as opposed to just reading through text so yeah just pictures and graphs and charts would be how I would be able to visualize it."* (Participant 016)

iv. Explanations of the purpose of the FOCUS-34 and its components. To further support utility of a digital solution, caregivers recommended incorporating (optional) explanations for various components of the FOCUS-34 to provide respondents with additional context when completing the form. More specifically, it was recommended that developers include a description of the purpose of the FOCUS-34, examples or explanations to help caregivers differentiate items asking them to rate verbal versus non-verbal communication behaviours, and additional information to support caregivers in interpreting the Likert scale descriptors. To clarify the purpose of the FOCUS-34, explanations were recommended for what the tool is, why families are asked to complete it, and when and why it will be completed again.

> *"Knowing and even just sort of setting the expectation of like okay you're doing the survey at intake but we're hopeful to do it again at certain intervals. Just knowing that when you enter the program okay, we're going to be doing this twice a year, and that we will see the progress if any that will be made and that's why we're doing it."* (Participant 005)

To ensure clarity regarding individual FOCUS-34 items and Likert scale descriptors, caregivers suggested incorporating optional explanations to support consistent completion. Participants felt these explanations could be text, audio, or video-based and may appear as a pop-up option or as part of a Frequently Asked Questions page.

> *"This is what this means, and you know if you don't need that explanation you don't have to have that open. I'm just thinking of it from a tech perspective, like it could just be optional to see a definition of that question."* (Participant 007)

v. The ability to communicate with the SLP. Many caregivers expressed the desire to be able to send comments, observations, feedback, or questions to their SLP as part of the outcome measurement process. Caregivers believed this type of feature would make services more collaborative and may provide additional context to their ratings.

> *"Just maybe like an area for a parent to track their thoughts and whatnot, like little comment section that they can look back on and be like "Oh yeah, I forgot that that's something that I was working on", and you can look back on how its developed or how it's gotten better over time."* (Participant 016)

vi. A reminder system. Due to the busy nature of their lives, caregivers said they would appreciate a built-in reminder system to notify them when it was time to complete the FOCUS-34. A reminder system was also reported to be useful for notifying caregivers if they missed rating an item, and one suggestion was for the solution to colour-code rated versus un-rated items.

> *"Yeah, or you know like with Facebook messenger how it will have a little red with a number for how many messages are waiting in your inbox? If there's a little dot here so pay attention this looks different than it does every other day."* (Participant 013)

> *"In a little grid at the top and then like it's yellow if you haven't answered it yet it's green if you have, and then I can click back to the yellow ones at the end."* (Participant 012)

Suggested Formats. Caregivers had varying opinions about the preferred format for a digital FOCUS-34, and they debated the benefits and limitations of a digital application (App) as compared to a web link. They also discussed the importance of having an in-house option regardless of the selected format. Perceived benefits for each format are summarized in Table 6, and perceived benefits and limitations for each format discussed are presented next.

Table 6

Caregivers' perceived benefits of digital application, weblink, and in-house options for a digital FOCUS-34.

FEATURES	DIGITAL APPLICATION	WEB LINK	IN HOUSE OPTION
Consolidation of Information	●	●	
Cloud Data & Synched Information	●	●	
Notification and Reminder System	●		
Storage and Device Compatibility		●	
Provides Assistance (technology, personnel)			●

i. Benefits and limitations of an App. A digital application on a smart or mobile device was viewed as beneficial as it would allow caregivers to consolidate, store, and synchronize information using a cloud-based platform. Participants felt an App would be accessible as they believed most caregivers used mobile and smart devices (e.g., smart phone, iPad, tablet). An App was said to provide more immediate notifications, which caregivers thought would help remind them to complete the FOCUS-34. Caregivers said they were willing to sacrifice storage space to download a FOCUS-34 App if they felt it would be useful for them or their child.

> *"It would be a useful App to have - it's not like it's going to bog down your phone or anything like that."* (Participant 014)

Despite the above-mentioned benefits, caregivers cautioned that having to download an App may introduce a barrier to participating in outcome measurement for some families. They also questioned whether an App would be worth downloading given the number of times they would need to complete the FOCUS-34 (currently approximately twice annually), and noted that a digital application could be prohibitive for those with technology that was not compatible, those with limited technical skills (e.g., unable to download, uncomfortable navigating Apps), and those with limited digital storage (e.g., phone storage filled with important videos, photos and other Apps).

> *"I have an App for everything and if we only use it, like every six months, or something I don't want yet another App"* (Participant 012)

ii. Benefits and limitations of web links. Weblinks were viewed as accessible as participants believed most caregivers had an email address. Other perceived benefits were that weblinks would allow for cloud-based storage, would let caregivers to conveniently share information, and could be convenient for those without data on their device.

> *"Links are also more accessible. I think you're hard pressed to find somebody who doesn't have an email address these days"* (Participant 003)

A perceived drawback to a web link was that caregivers felt they posed no urgency, which could result in lower completion rates. The majority of caregivers also felt a link could get lost in email clutter, making it difficult to find and store.

> *"I would forget about it, that's me. Links are hard like it's something that's there but what is this going to be - in your email? Like where would you keep your link, you know what I mean?"* (Participant 014)

iii. Preferred and compatible technology. Regardless of format, caregivers had varying views about which device they would use to complete a digital FOCUS-34. Many felt the solution should be accessible from a smartphone or mobile device so the FOCUS-34 could be completed quickly. Another perceived benefit to smart or mobile devices was that they may mitigate issues related to internet access because caregivers could use cellular data.

> *"You can do it on your phone, and you can use your data, and data is a lot faster."* (Participant 001)

While many preferred mobile technologies, some reported feeling more comfortable completing sensitive or important documents on a desktop or laptop computer. Others noted a desktop or laptop computer may be more accessible due to the larger screen sizes. A larger screen was also viewed as useful for involving other caregivers in the outcome measurement process. However, it was mentioned that completing forms on the computer would require additional time.

> *"I still use a desktop computer like that's what I'm using right now. I don't do anything that I would deem important on my phone. I might shoot a quick email or something from my phone."* (Participant 003)

> *"Through the computer seems to be a little easier. It's more opportunity for more parents to be involved, which would only benefit the child."* (Participant 002)

iv. The need for an in-house option. Participants stressed the need to provide an in-house option for those who may not have access to a phone, computer, or the internet. Participants felt an in-house option could be completed in a timely way and would have the added benefit of allowing caregivers to complete the FOCUS-34 together with their child's SLP.

> *"They would be familiar with how to use an iPad and fill it out, and if they weren't, then somebody would be there to assist them in doing so, so I don't know that there are really any barriers."* (Participant 001)

Other suggested considerations. Participants discussed other factors they felt were important to consider for a digital solution. Identified factors included accessibility and the timing for when families received scores in relation to when they would next see their SLP.

i. Accessibility. Accessibility was viewed as critical, and multiple considerations were flagged. One concern was ensuring the digital solution would be available for *all* families, including those in Northern and rural Ontario where internet access may be limited or unstable. Participants from these regions explained that many families did not use or have regular access to the internet.

> *"I can see other barriers for families that don't have access to the Internet or to phones which you can see a lot of here in northern Ontario. Some people don't have Internet in their homes believe it or not, and a lot of people live out in the country, so that might not be as accessible to them."* (Participant 016)

Technology access and technology literacy were also identified as potential accessibility issues, with participants suggesting some families may lack the technology required to complete the digital FOCUS-34 (e.g., no desktop computer), or be unfamiliar with how to navigate or use the required technology.

"Families with all this digital stuff, that could be challenging for them to access." (Participant 003)

Finally, language and literacy were identified as potential access barriers for Ontario families. As such, participants recommended providing multiple ways for families to complete the FOCUS-34. Accessible options included the ability to select from multiple languages for those whose first language was not English, closed captioning for those with hearing impairments, and the option to use audio to listen to FOCUS-34 items and Likert scale options for those with literacy challenges or visual impairments. Participants also recommended reducing or removing technical jargon wherever possible, which they felt could be intimidating for caregivers.

> *"From a parent's standpoint, it can be very intimidating."* (Participant 009)

ii. Timing of feedback. Lastly, considering the timing for when caregivers received scores and when they would next see their SLP was viewed as important. Most caregivers expressed their need to see results immediately, regardless of whether they were with their SLP. Caregivers felt immediate access to results would give them time to process the information and generate questions to ask their SLP when they next met. All participants described wanting to meet with their SLP shortly after receiving scores.

> *"I think I would like to see it myself and then also discuss it with the SLP at an appointment because if you're just presented with the information on the spot at the appointment you don't necessarily have as much time to sort of read through it and think about the questions that you'd like to ask, and look at maybe the nuances of what's being said. Whereas if I can look at it at home ahead of time, I have more time to reflect on it, and then I feel like I can ask more relevant questions."*
> (Participant 003)

A few caregivers said that their desire to see scores alone would be dependent on whether results were positive or negative. For example, receiving scores that were negative or showed no progress may have a negative impact without context or support from the SLP.

> *"I was thinking about even like for myself, even if the graph weren't going up. I obviously want to see the graph going up over time, but if it plateaued or they lost skills, then I definitely I think that I would be fine doing it on my own getting the results right away, as long as it was within like 24-48 hours of my in person talk with the SLP so that I don't get those scores and then my appointment is in three weeks, like that's too long for me to worry about it."* (Participant 012)

Chapter 4 - Discussion

There is limited evidence documenting caregivers' experiences with outcome measurement in speech and language therapy. This study engaged caregivers of preschoolers with communication difficulties who were accessing services in one large publicly funded health system in virtual focus groups and individual interviews to understand both their experiences and needs related to outcome measurement. More specifically, this study aimed to understand caregivers' experiences completing the FOCUS-34 and learn whether and how a digital solution may improve their user experience. Caregivers who participated in this study were unsure about the purpose of the FOCUS-34, reported needing support to complete it, and believed a digital solution could improve their service experience. They also identified important features to be included in a digital solution from the perspective of families. Overall, results revealed inconsistencies with current FOCUS-34 measurement procedures, and highlighted caregivers' needs for standardized and clear administration procedures and desires for more feedback regarding their child's performance on the FOCUS-34. Results are discussed within two areas: (1) caregivers' confusion about outcome measurement and their need for support and (2) caregivers believed that a digital solution with specific features would improve their user experience.

4.1 Caregivers' Confusion about Outcome Measurement and Need for Support

Caregivers experienced difficulties completing the FOCUS-34 due to inconsistent administration procedures, differing expectations about outcome measurement, and a knowledge gap related to communication terminologies. Many caregivers felt uncertain about the purpose of the FOCUS-34 as they did not receive any explanation or instructions when they were asked to complete it or feedback about their child's performance. A lack of transparency about the measurement purpose, process, and outcomes may also impact caregiver satisfaction with services, which is known to be affected by the information families receive from their clinician (King et al., 2001). For instance, King et al. (2001) found that caregivers were satisfied with services when their clinician provided information about children's progress through written reports and responses to questions

(King et al., 2001), but dissatisfied when clinicians did not provide satisfactory information about children's progress (King et al., 2001). The observations reported in King et al. (2001) align with results from the current study which identified caregivers' dissatisfaction regarding the lack of information sharing about children's FOCUS-34 results. In the current study, caregivers expressed feelings of sadness when providing low ratings for their child who was younger or had limited communication skills which may have led to negative or indifferent perceptions about services, which are known to be associated with engagement with and attitudes about therapy (Phoenix et al., 2020).

Similarly, a lack of transparency surrounding the outcome measurement purpose and process may impact the delivery of family centered services. Effective communication and collaboration between caregivers and SLPs are essential in a family-centered approach to care – which conceptualizes a child's needs within the context of their family system by considering family choice and needs, and prioritizes family-professional communication (Hampton et al., 2022). A family centered approach to care is promoted and supported in the PSL program yet results of the current study suggest this approach was not being fully realized as caregivers were not provided with key information about children's outcomes. Clear communication about the purpose of the FOCUS-34 and its results is likely to improve caregivers' understanding about the outcome measurement process and build a stronger foundation for caregiver collaboration to support the delivery of more family centered services moving forward (Hampton et al., 2022).

There is evidence to support the idea that caregivers have a range of expectations regarding speech-language services and outcomes (Phoenix et al., 2020), which may have impacted their experiences engaging with the FOCUS-34. These expectations are often subliminal and require clinicians' explicit attention (Phoenix et al., 2020). For example, parents' therapy related expectations are often initially shaped by existing knowledge of child development when concerns with age-expectant behaviours are identified, social comparisons are made, and knowledge is gained from online or social sources (Phoenix et al. 2020). Caregivers' service expectations may also be related to expectations associated with their child's diagnosis (Phoenix et al., 2020). If expectations influence what parents expect in therapy, they are also likely to extend to the types of outcomes they expect their clinician to measure and report. Many caregivers in the current study expected outcome measurement to align with and report on comparisons to normative data, which was different from the intended purpose of the FOCUS-34 as an outcome measure. This posits a misalignment between families' expectations and the PSL program's focus on functional and participation-focused outcomes. Thus, it is critical for clinicians to engage parents in all aspects of service delivery, including outcome measurement, and to consider and address caregivers' expectations early in the therapy process so they are realistic and well-aligned with service goals and targeted outcomes (Melvin et al., 2019; Phoenix et al., 2020). Clinician-caregiver discussions about expectations before service starts may be particularly important for facilitating caregivers' collaboration and engagement (Lyons et al., 2010). Improved communication about the purpose and function of the FOCUS-34 is therefore recommended to ensure caregivers' expectations are aligned with the program's outcome measurement goals early in a family's service experience (Donaldson et al., 2004).

Finally, in addition to a lack of information about purpose and results, caregivers expressed difficulties understanding some terms used in the FOCUS-34, which they felt made it hard for them to complete the measure accurately. Confusion around terminology was most often related to items that required caregivers to differentiate verbal versus non-verbal communication skills - terms that may have been perceived as clinical or medical jargon. This aligns with findings from an interview study with SLPs where clinicians questioned the validity of the FOCUS data due to some families reporting that they struggled to comprehend some individual FOCUS items (Kwok et al., 2022). Studies indicate caregivers' desire for clinicians to share information, but to do so using less medical jargon, which is viewed as limiting parents' understanding of their child's assessment results (Arcuri et al., 2015; Donaldson et al., 2004). The use of medical jargon has also been reported to make parents feel incompetent when communicating with their clinician (Donaldson et al., 2004). To reduce confusion and improve engagement, caregivers in this study recommended providing clarification or support regarding the terminology used in some FOCUS-34 items. This finding aligns with recommendations from PSL program clinicians in another study, who recommended improving the clarity and readability of the FOCUS-34 to support families in completing it (Kwok et al., 2020). Possible solutions are to provide descriptions and examples for items that have been flagged as containing clinical jargon (Donaldson et al., 2004), a potential solution also identified by caregivers in the current study. Another solution is to ensure caregivers can complete the FOCUS-34 with their SLP so that questions can be asked and answered.

4.2 Caregivers Believe a Digital Solution with Specific Features Would Improve User Experience

In an increasingly digitized healthcare system, digital solutions such as electronic measurement tools offer potential avenues for increased engagement, equity, and accessibility for caregivers (Dunham, 2011; Lin et al., 2021). The increase in access to digital tools is evident in the field of speech-language pathology, where digital solutions such as online speech therapy systems are being used to assist with diagnostic evaluations (Lin et al., 2021; Attwell et al. 2022). With increasing technological advancements, originally pen-and-paper questionnaires like the FOCUS-34 are being digitalized because of identified benefits including feasibility and accessibility (Beckers, 2021). There are many benefits to digitizing assessment tools as they have the potential to improve client motivation, streamline data-capturing, and provide a visual and interactive presentations of results (Edwards et al., 2017).

Caregivers in the current study identified multiple benefits to a digital solution for the FOCUS-34, including that it could improve feasibility, engagement, and transparency associated with the outcome measurement process. Caregivers also noted that by consolidating data in a centralized place, SLPs and families could both easily access the same information, which would improve transparency and timely communication. Importantly, caregivers wanted the ability to review and compare their children’s previous FOCUS-34 scores and reflect on changes. They suggested that a numeric and visual presentation of FOCUS-34 results would help them to conceptualize their child’s development across total and profile scores. Specific to visual feedback, caregivers provided clear suggestions for how to display FOCUS-34 results digitally so they would be easily accessible, clear, and understood such as through colourful visual graphs that accompanied written explanations to better depict profile scores. These recommendations align with previous research that identified parents' recommended features for pediatric speech-language therapy Apps, which included the ability to collect and store data and visualize children's progress over time to provide them with feedback and positive reinforcement (Du et al., 2022). Caregivers' recommendations also align with features commonly found in online speech therapy systems such as the ability to provide statistical reports about a child's progress, access to data related to the child, and visual feedback for results (Atwell et al., 2022). A digital solution for the FOCUS-34 was also recommended by clinicians interviewed by Kwok et al., (2020) as a way of supporting clinical implementation. More specifically, it was believed a digital FOCUS-34 would enhance the tool's clinical utility by allowing clinicians to access, calculate, and interpret scores.

A digital solution that streamlines FOCUS-34 administration, data collection, and data submission and access could provide immediate access to change scores for both caregivers and clinicians to improve participation-focused outcome monitoring (Kwok et al., 2020). A digital solution could also enhance the delivery of family-centered services by providing caregivers with timely access to information so they can be involved as key partners in decision making about their children's speech-language pathology services (King et al., 2001).

4.3 The Value of Engaging Caregivers in Research

As caregivers are key end-users of the FOCUS-34 it was critical to engage their perspectives in any work aiming to modify or improve the tool. Engagement with caregivers is described as empowering them to take an active role in their child's services, which can include both assessment and intervention and may involve engagement both during and outside of face-to-face appointments (Melvin et al., 2019). Successful engagement is identified as an important factor for optimal service delivery and improved outcomes for both children and families in a range of service settings as it can improve parental satisfaction with services, treatment outcomes, and homework completion (Melvin et al., 2019).

The ideas presented related to caregiver engagement in services can also apply to research, and the patient-oriented research approach (CIHR, 2019). Caregivers involved in this project became active participants in the research process by sharing their current outcome measurement experiences, and future needs to inform the future development of a digital solution for the FOCUS-34. Engaging caregivers early in the development process will help ensure the final product is relevant and meaningful to them (Rosenbaum, 2011), which could lead to improved buy-in for outcome measurement, and subsequently improved communicative health services and positive health outcomes for children and families.

4.4 Thoughts on Virtual Focus Groups

In our view, engaging families through online virtual focus groups and individual interviews was feasible and allowed for the collection of comprehensive data related to caregivers' experiences. Virtual data collection allowed us to interact with more Ontario families than would otherwise have been possible, as we were able to engage families across a wide geography including Northern Ontario and smaller communities. The opportunity to engage with families from different regions allowed for dialogue between participants who may not have otherwise spoken with one another (Quach et al., 2013). This could have improved the richness of data as the virtual focus groups allowed for participants to discuss ideas with others who may have had different experiences in their respective regions (Woodyatt et al., 2016).

The virtual nature of our focus groups also allowed for more flexibility and convenience for study participants in terms of finding time in their busy lives to attend, and limited costs associated with participating in research such as having to drive to a specific location (Galarza et al., 2021). This may have allowed us to recruit participants whose perspectives we would not have otherwise heard. Providing participants with the ability to participate in their homes may also have allowed for improved participation in the group discussion by increasing participant anonymity to facilitate conversation more comfortably and openly (Woodyatt et al., 2016). Virtual data collection benefited the research team as it was feasible given the study budget, allowed for the collection of potentially diverse perspectives, and provided automatic and highly accurate transcription of qualitative data, potentially reducing transcriber bias (Tates et al., 2009).

4.5 Reflections on Focus Groups versus Individual Interviews

Focus groups were chosen as the primary methodology for this study because of their ability to help participants share their views and ideas, while also benefiting from hearing the perspectives of others, which may have helped to optimize the generation of new ideas in a way individual interviews cannot (Coenen et al., 2011). A study by Coenen et al. (2011) compared costs associated with and results obtained from focus groups and individual interviews. The authors reported that the ideas generated among focus group participants allowed others to voice similar experiences, and to comment, explain, disagree, and share attitudes (Coenen et al., 2011). However, focus groups were reported to take more effort as logistic problems such as scheduling a convenient meeting time was difficult (Coenen et al., 2011). These reported benefits and limitations were consistent with our experiences, as some interested caregivers were unable to attend any of the focus group times and were therefore interviewed individually. The benefits of individual interviews are that participants may feel freer to answer interview questions and discuss personal topics in depth, and that transcription may be less challenging (Coenen et al., 2011). This aligned with the current study where caregivers in individual interviews were informally observed to be more inclined to describe their child’s communication and therapy progress with the moderator and co-moderator unreservedly. Cumulatively, we believe both focus groups and individual interviews were effective for developing an in-depth understandings of caregivers’ experiences with the FOCUS-34.

4.6 Study Limitations

Some limitations of this study include a lack of diversity in the participant sample, potential selection bias, and confirmation bias. Based on the demographic survey, all study participants identified as Caucasian, highly educated, and within the upper socioeconomic strata. According to 2022 Ontario statistics, 4,817,360 (34%) of individuals identified as being a visible minority

(Government of Canada, Statistics Canada, 2023), and in 2020 the median Ontario household income was $79,500 and almost a third (30%) of Ontarians aged 15 and older had a university degree (Government of Canada, Statistics Canada, 2023). Unfortunately, the study sample was not diverse or representative of all Ontario families, and as such, findings may not be generalizable or relatable for all families, particularly for those who identify as racialized, have differing levels of education, or come from other socio-economic statuses. The lack of diversity in our participant sample may have been due in part to the requirement for participants to have English language proficiency at a conversational level, as it has been reported that diverse racial/ethnic groups are often less represented in clinical research due to psychosocial and cultural barriers such as lower income, poor education, and lack of proficiency in the language the study is being conducted in (Shea et al., 2022). Other potential participation barriers in the current study may have been associated with the requirements for online data collection and remote participation, which may not have been accessible for caregivers with technology constraints. Limited technology access or literacy may have also restricted participation and diversity in the sample, leading to potential sampling bias associated with age or socioeconomic status (Tates et al., 2009).

Our recruitment strategy utilized convenience sampling to identify families receiving services in the PSL program, which may also have introduced bias. While programs and clinicians were asked to purposefully consider diversity when inviting families to participate, it is possible they may have only asked some families or that only a certain type of caregiver agreed. For example, it is possible that only caregivers who felt strongly about outcome measurement or the FOCUS-34 agreed to participate (Sousa et al., 2004).

Lastly, confirmation bias – defined as seeking explanations in ways that give priority to confirming a pre-established belief – may have been present in the focus groups (McSweeney, 2021). Previous research regarding the FOCUS-34 included SLPs who indicated that a digital solution would be helpful (Kwok et al., 2020a), however caregivers were not part of this process. The research team formulated a hypothesis based on the recommendations by Kwok et al. (2022) by anticipating that caregivers would want a digital solution. However, it is possible that participants may have identified a different solution had more open-ended questions been asked.

4.7 The Importance of Positionality

Utilizing my positionality allowed for a more nuanced understanding of the data that might not have been immediately obvious without bringing my own experiences, beliefs, and assumptions to the research process. For example, when identifying codes and themes related to a digital solution, I tried to ensure considerations related to power and equity were represented because I wanted the digital solution to be culturally appropriate and accessible for all Ontario families. I also purposefully reflected on my personal biases and considered how they may have influenced my interpretation of the data because I did not want to speak for marginalized caregivers or assume I understood their needs with respect to the FOCUS-34. To do this, I worked with my team to describe why I chose to code things in certain ways and to ensure I was flexible in my interpretation of the data. I used this to create a meaningful story about caregivers’ experiences with and expectations for the FOCUS-34.

4.8 Implications for Research and Practice

This thesis aimed to understand caregiver experiences and expectations with the Ontario PSL program’s outcome measurement process. Results will support the PSL Program by informing future efforts to improve clinical utility of the FOCUS-34 as a participation-focused outcome measure. Results will also be used to address families’ concerns regarding the FOCUS-34 and improve outcome measurement services within the PSL program regardless of whether a digital solution is developed. This includes work to understand the impact and effectiveness of the FOCUS-34 in clinical settings and recognize how data are being interpreted and used by caregivers. Study findings demonstrate an immediate need for SLPs to understand caregiver expectations before and throughout the outcome measurement process, provide clear explanations regarding the purpose of outcome measurement, explain profession-specific terminology, and ensure caregivers receive feedback about children’s scores.

Beyond the scope of the PSL program, findings from this study contribute new knowledge to the growing body of literature regarding the integration of caregiver perspectives in speech-language pathology research. Future research could aim to further improve implementation of the FOCUS-34 by creating a digital solution that integrates caregivers' identified needs and recommendations. To support this work, focus group results were integrated into a requirements document to guide the design of a digital solution for the FOCUS-34 based on caregivers' needs (Kotonya & Sommerville, 1998; Paetsch et al., 2003). The requirements document will provide an outline for what to build before development starts to ensure the digital solution incorporates user needs, and features and functions that are important to them (Kotonya & Sommerville, 1998; Paetsch et al., 2003). A preliminary requirements document is presented in Appendix C.

Findings from this study with caregivers will be integrated with those from a parallel study being conducted with clinicians to begin to address the technical shortcomings of the FOCUS-34 formats and additional gather insight into how best to digitize this outcome measure. Ultimately, findings from both studies will be used to inform the digitization of the FOCUS-34 to ensure it meets the needs of multiple end user groups. Once developed, the digital solution could be tested and evaluated by both caregivers and SLPs. If developed, a digital FOCUS-34 must improve families' experiences with outcome measurement and speech-language pathology services to better understand the impact of services on children's communicative participation, and to support goal setting and collaborative service planning.

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Appendix A: Preliminary Demographic Survey

Thank you for agreeing to participate in our quality improvement project. This project is supported by the Ontario Ministry of Children, Community, and Social Services. It aims to understand caregivers' experiences completing the FOCUS-34 as part of the services they receive in the Ontario Preschool Speech and Language Program. More specifically, the project aims to understand how parents' experiences could be improved (e.g., through the use of technology).

This initial survey is designed to collect some basic demographic data to help us describe our participants. Your name is required to confirm completion of the survey prior to your focus group but will be removed from the data and replaced with an anonymous identification number immediately after your focus group session. The information you provide may be synthesized with responses from other parents and reported in a publication, but individual data will never be shared beyond the research team at Western. Raw data (i.e., your individual responses to questions) will only ever be accessible to the research team at Western.

Thank you for sharing your time, knowledge, and experiences with us.

You will first be asked to answer some questions about yourself and your family.

Please enter your first and last name	______________________________
Please enter the gender you identify with	○ ○ FemaleMale ○ Self-Identify
Please tell us how you self identify.	______________________________
Which ethnic or cultural background(s)/origin(s) doyou identify with? (check all that apply)	☐ Arab/West Asian (e.g., Armenian, Egyptian,Iranian, Lebanese, Moroccan) ☐ Black (e.g., African, Jamaican, Somali)Caucasian ☐ ChineseFilipino ☐ First Nations/ Metis/ InuitJapanese ☐ Korean ☐ Latin-American ☐ Southeast Asian (e.g., Cambodian, Indonesian, ☐ Vietnamese) ☐ Other ☐
Please tell us which ethnic or cultural background(s)/origin(s) do you identify with.	______________________________

What is the highest level of education you have completed?	○ Some high school credits ○ High school certificate or diploma ○ Apprenticeship or trades certificate or diploma ○ College or other non-university certificate or diploma ○ University certificate or diploma (e.g. Bachelor's)Post- ○ graduate certificate or diploma (e.g. Master's, PhD)
Do you do paid or volunteer work outside your home?	○ Yes ○ No
How many children do you have?	______________________________
Please list the ages of the children (in years) wholive with you full or part time.	______________________________
How many people (in total) live in your home?	______________________________
Do any other adults live in your home?	○ Yes ○ No
How are the adults in your home related to you?(select all that apply)	☐ Spouse/Partner ☐ Parent(s)/In-law(s) ☐ Other
How are the adults in your house related to you?	______________________________
Please indicate the category that best describes your total family income last year before taxes.	○ Less than $20 000 ○ $20 000 to $39 999 ○ $40 000 to $59 999 ○ $60 000 to $79 999 ○ $80 000 to $99 999 ○ More than $100 000
What size is the community you live in?	○ Large urban population centre (population over 100000) ○ Medium population centre (population from 30 000to 99 999) ○ Small population centre (population between 1,000and 29,999) ○ Rural community (population less than 1 000)

What geographic region of Ontario do you live in? (approximate location)

○ Northern - (approximately Parry Sound and North of Parry Sound)
○ Southwestern (approximately Windsor to Oshawa)
○ Eastern (approximately Peterborough to Cornwall)

Next you will be asked to answer some questions about your use of technology.

Do you personally own any of the following technology (select all that apply)	☐ ☐ Tablet Smart ☐ phoneLaptop ☐ Desktop computer ☐ Other
What other piece(s) of technology do you own?	____________________
Please rate your level of experience using a computer keyboard/mouse.	○ Beginner ○ Average ○ Above Average
Please rate your level of experience using a laptop/desktop computer.	○ Beginner ○ Average ○ Above Average
Please rate your level of experience using mobile devices (smartphones/tablet).	○ Beginner ○ Average ○ Above Average
Please rate your level of experience using applications (Apps) on mobile devices.	○ Beginner ○ Average ○ Above Average
Please rate your level of experience using videoconferencing technology.	○ Beginner ○ Average ○ Above Average

Third, you will be asked some questions about the child for whom you have completed the FOCUS-34.

Please indicate the gender of your child for whom youhave completed the FOCUS-32.	○ Female ○ Male ○ Self-Identify
Please tell us how your child self-identifies.	______________________________
What is your child's current age in months(e.g., A 2.5 year old is 30 months old)?	______________________________
Please describe your child's challenges with communication (i.e., the reasons they are receiving support from the Ontario Preschool Speech and Language Program).	______________________________________
Does your child have any developmental concerns in addition to speech and language? (check all that apply)	☐ Acquired brain injury ☐ Autism (or suspected Autism) ☐ Cerebral Palsy Cleft ☐ lip and/or palate ☐ Developmental Coordination Disorder ☐ Epilepsy ☐ Fetal Alcohol Spectrum Disorder ☐ Genetic condition/syndrome ☐ Global developmental delay or suspected GDD ☐ Motor impairment (gross or fine) ☐ Neurodegenerative condition ☐ Permanent hearing loss (not ear infections)Velopharyngeal ☐ insufficiency ☐ Visual impairment ☐ None ☐ Other
Please describe your developmental concerns.	_____________________________________
The Communication Function Classification System (CFCS) is a tool to describe how children use their communication in everyday interactions. The tool doesnot consider age, only how children function. For example, a typically-developing 2-year old wouldbe a level IV (inconsistent sender/receiver) because they don't consistently express or understand all attempts at communication. How would you classify your child's functional communication skills?	☐ CFCS Level I - Effective Sender and Receiverwith unfamiliar and familiar partners (e.g., neighbours, teachers, parents/caregivers) ☐ CFCS Level II - Effective (slower paced) Sender and/or Receiver with unfamiliar/familiar partners (e.g., neighbours, teachers, parents) ☐ CFCS Level III - Effective Sender and Receiver with familiar partners (e.g., parents/caregivers) ☐ CFCS Level IV - Inconsistent Sender and/or Receiver with familiar partners (e.g., parents/caregivers) ☐ CFCS Level V - Seldom Effective Sender and Receiver even with familiar partners (e.g., parents/caregivers) ☐ I'm not sure
What is your relationship to your child?	○ Parent ○ Caregiver ○ Other
Please describe your relationship to your child.	______________________________

Finally, you will be asked about your experiences completing the FOCUS-34 in Ontario's

Please tell us how many times you have completed theFOCUS-34 for your child.

Never ○ 1-2 times ○
3-5 times ○ 5+ times ○

Have you received any training (formal or informal) regarding completing the FOCUS with speech-language pathologists (SLPs)?	Yes No
Please describe the training (formal or informal) youreceived for completing the FOCUS-34.	______________________________
Do you complete the FOCUS-34 together with a speech-language pathologist?	○ Yes No ○ Sometimes
Do you know why you are asked to complete the FOCUS-34?	○ Yes No
Has your speech-language pathologist ever discussed your child's FOCUS-34 scores and what they mean withyou?	○ Yes No
Do you find completing the FOCUS-34 helpful for understanding your child's functional communicationskills?	○ Yes No

Gift cards!

We will be sending you a $40 gift card as compensationfor the time you have spent completing this survey as well as the time you will spend in your virtual focus group.

Please indicate your preference for an e-gift card.

○ Amazon
○ Indigo
○ Shoppers DrugMart
○ Starbucks
○ Tim Horton's

Appendix B: Focus group questions

Duration in Minutes	**Task**
12	**Introductions**
5	Introducing moderator, assistant moderator and BJ Cunningham, ask participants to introduce themselves to the group
2	Purpose of focus group (brief overview)
2	Discuss ground rules of focus group
2	Explain how the team will ensure confidentiality of participants' comments
8	**Create Familiarity with Group & Topic of discussion**
3	Ice Breaker
5	Description of the intended purpose/use of the FOCUS within the Ontario PSL Program (Dr. BJ Cunningham)
12	**Group Question 1 – What has been your experience completing the FOCUS-34 for your child as part of their service in the Ontario PSL Program?**
	Probe: *What is your understanding/what have you been told about why you are asked to complete the FOCUS-34?*
	Probe: *What feedback did you get from your SLP regarding how your child scored/whether they made change?*
	Probe: *Have you completed the F-34 together with your SLP or on your own? What's that like?* • *How important is SLP interaction for completion of the FOCUS?* • *What are the benefits/challenges of completing the F-34 without the SLP?*

Duration in Minutes	Task
12	**Interview Question 2 – What information about changes in your child's functional communication would be helpful for you to have following speech-language therapy?**
	Probe: *What scores would you need to see (have displayed) to help you understand (e.g., change/profile scores)?*
	Probe: *Would you like to see how your child changes over time?*
	Probe: *Do you want to see profile scores (or change in profile scores)?*
	Probe: *Would you want/need support with interpreting scores? (e.g., what to say about change/no change)?*
	Probe: *How would you want information displayed so you could use/interact with it?*
	Probe: *Do you want to see comparison data (e.g., compare scores to others of same age/level)?*
15	**Interview Question 3 – If the FOCUS-34 was made available in a digital format, what might be the barriers and facilitators to families using it?**
	Probe: *What delivery format would be best (online, app, in house)?*
	Probe: *Would you be comfortable with using a digital solution (e.g., App)?*
	Probe: *Are there accessibility considerations (e.g., low vision/hearing, ESL, low literacy)?*
15	**Interview Question 4: How might a digital solution for the FOCUS-34 be useful or impactful for your family?**

	Probe: *What info do you would be helpful for you to see?*
	Probe: *Would you want to see your child's scores immediately or when you are with the SLP?*
	Probe*: Do you think families would have difficulty interpreting the information?*
	Probe: *How do you want to see those variables over time? Is there a figure that would be helpful?*
	Probe: *Should there be different displays for clinicians/families?*
	Probe: *Would built-in analyses improve clinical utility (e.g., change or comparison scores)?*
5	**Interview Question 5 (Concluding Exit Question)**
	What other elements could be included in a digital version of the FOCUS-34 to make it more useful for your family?
Total Time in Minutes	
~60 minutes	

Appendix C: Requirements Document

Suggested Features, Displays and Functions	Description
Show and Explain Change and Profile Scores	○ Provide FOCUS-34 total, change, and profile scores and guidance for how to interpret these scores ○ Explain when change is meaningful/significant ○ Include reasons for possible outcomes (e.g., change, no change, or regression) to support data interpretation, and describe how expected change may vary based on a child's age and stage ○ Identify child's communication strengths and weakness based on scores (e.g., "child is strong in these non-verbal categories") ○ Previously completed FOCUS-34 forms should be stored and easily accessible for caregivers to compare ○ Useful for tracking change and to see how they answered questions previously ○ Caregivers and SLPs should receive the same timely feedback to avoid confusion/improve transparency

Display Options for FOCUS-34 completion	○ Provide users with item display/presentation options <u>before</u> completing the measure
	    ○ Singular questions (have items presented one at a time and have user click "next" to p\roceed to next question)
	        ▪ Option to go back to previous questions or move forward/skip questions to revisit later is important for this feature
	    ○ Have all questions present on same page (present all 34 items and have users scroll vertically to answer items)
	○ Present items in categories (e.g., all non-verbal communication items together) to facilitate comprehension for completion

Visual Display of Results	○ Display results using colourful line graphs to show change in total, change, and profile scores to support interpretation

Optional Explanations for the Purpose of the FOCUS-34 and its Components	○ Explain the purpose of the FOCUS-34
	    ○ Describe the purpose of the FOCUS-34, explain why families are asked to complete it, and when/why it will be completed again
	○ Optional notes to help users interpret and differentiate individual FOCUS-34 items
	    ○ Provide context through examples and explanations (e.g., describe "verbal" vs. "nonverbal")
	○ Optional notes to help users differentiate Likert scale descriptors (e.g., "a little" vs. "somewhat")
	○ Provide written and/or audio/video-based explanations for the concepts above as optional pop-ups
	○ Include a Frequently Asked Questions page

Ability to Communicate with the SLP	o Section/feature where users can write/store comments to contextualize their FOCUS-34 ratings and/or share observations about their child with the SLP
Reminder System	o Reminder system that notifies user when it is time to complete FOCUS-34 through alert, banner, email reminder, etc. o Colour code completed versus uncompleted items to flag missed items (ex. green for completed items, yellow for items that have not been rated)
Accessibility	o Consider accessibility for all PSL Program families o Technology Access and Technology Literacy: consider families who may lack certain technology or who are unfamiliar with how to use technology o Language and Literacy: consider how accessible information, language and words are for all users ▪ Language Options with selection of multiple languages for users whose first language is not English ▪ Closed Captioning for those with hearing impairments ▪ Audio Listening for those with literacy challenges or visual impairments ▪ Increased Font Size for those with visual impairments ▪ Removing/Reducing Technical Jargon by using lay friendly terminology
Timing of Feedback	o Automatic and immediate access to results, scores, and explanations after completing the FOCUS-34 o Provide results to families regardless of whether they are with their SLP

Curriculum Vitae

Name:	Sachin Kharbanda
Post-Secondary Education and Degrees:	Western University London, Ontario, Canada M.Sc., Speech and Language Sciences, Health and Rehabilitation Sciences 2021-2023
	Western University London, Ontario, Canada B.HSc., Honours Specialization in Health Sciences - Health and Aging 2017-2021
Honours and Awards:	Health and Rehabilitation Sciences Graduate Research Conference Best Poster Presentation (Educate), 2023
	Alternate Offer for the Canadian Institutes of Health Research Scholarship - Master's (2022-23)
	Alternate Offer for the Ontario Graduate Scholarship - Master's (2022-23)
	Graduate Research Fellowship, 2021-2023
Related Work Experience:	Health and Community Services Worker, 2021 Kitchener Downtown Community Health Centre
	Graduate Teaching Assistant, 2021-23 Western University

Reports:
Leyland, Z., **Kharbanda, S.,** & Cunningham, B. J. (2023). Parent Perspectives on Outcome Measurement Using The FOCUS-34 in the Ontario Preschool Speech and Language Program. 15 pages. Ontario Ministry of Children, Community and Social Services.

Conference Presentations:
Kharbanda, S. & Cunningham, B. J. Empowered Kids Ontario Spring Symposium, Toronto, ON, April 2023. “Engaging Caregivers to Inform Digitize Outcome Measurement in Pediatric Speech-Language Pathology.”

Kharbanda, S. & Cunningham, B. J. Health and Rehabilitation Sciences Graduate Student Research Conference, London, ON, February 2023. “Engaging Caregivers to Inform Digitize Outcome Measurement in Pediatric Speech-Language Pathology.”