

What parents want: A qualitative analysis of a parent-implemented intervention for autistic children

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Abstract

Background and aims: Guidelines regarding social cognitive interventions for autistic children suggest incorporating a holistic approach. This includes increasing the family's understanding of difficulties associated with autism, integrations of natural environments, and parents as active agents in the intervention while being supported for their well-being. The current availability of holistic parent-implemented interventions for autistic children is limited, with no qualitative understanding of how parents view the benefits for themselves or their children.

Method: The current study expands the literature regarding holistic approaches through a qualitative understanding of parent perceptions of a parent-implemented social communication intervention for autistic children (TalkAbility™), which incorporates a 6-month follow-up. This study sought to gain a deeper understanding from parents on their perceptions of a holistic approach, including the impact on themselves, their families, and their autistic child.

Results: Following Braun and Clarke's model of thematic analysis, data was coded into four themes: (a) communication difficulties, frustrations, and progress, (b) social relationships and concerns, (c) communication strategies, and (d) thoughts and emotions surrounding TalkAbility™.

Conclusions: Parents report that many components of a holistic approach are instrumental in encouraging social communication in their autistic child. Results highlight the importance of considering parent experiences regarding interventions for their child's social communication skills through a qualitative viewpoint.

Implications: Knowing the intervention aspects that parents view as most valuable allows targeted program modifications that reflect actual parent needs. Further understanding regarding the influence of holistic parent-implemented social communication interventions on child communication skills, parenting frustrations, and parent-child relationships is needed.

Keywords

Autism, social communication skills, thematic analysis, qualitative research, parent-implemented intervention

Autism is characterized by impairments in social communication and restricted or repetitive behaviors or interests (American Psychiatric Association, 2013). Early interventions for autistic children are instrumental for social development (Zachor et al., 2007); however, there are few that focus on parent training and incorporate parental support and education. Given that parents provide their children

with the most opportunities for social interaction on a regular basis and that parent-implemented interventions are the most cost effective and easily applied (Oosterling et al., 2010; Pickard et al., 2019), there is a need for more research on parent focused interventions. The current study provides a preliminary qualitative analysis of parent perceptions regarding a holistic parent-implemented social

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communication intervention for autistic children, TalkAbility™, to illustrate parent concerns and difficulties, and outline what they find most helpful in an intervention for their autistic child.

Autism

Characteristics of autism emerge early in development but may manifest differently in severity over the lifespan (Szatmari et al., 2015). The level of intellectual ability and language deficits contributes to the heterogeneous profile of skills in autistic children. Although many verbal autistic children demonstrate average scores on measures of IQ and structural (semantic and syntactic) language, and perform well academically, these children still experience difficulties with initiating and reciprocating social interactions (Bauminger, 2007) and other social communication skills (abilities used to interpret, manipulate, and understand social information in order to solve problems in the social domain; Staub & Eisenberg, 1981). The social communication impairments experienced by autistic children often make it challenging to not only establish social relationships (Cresswell et al., 2019), but maintain them with both peers and family members (Bauminger & Kasari, 2000). Studies show that compared to children with and without other disabilities, verbal autistic children have fewer reciprocated friendships (Bauminger-Zviely, 2013), have friendships with less security and intimacy (Locke et al., 2010), spend less time socializing with peers outside school settings (Kuo et al., 2011), and report feelings of loneliness even though they indicate having at least one friend (Bauminger & Kasari, 2000). This often results in limited social networks outside of the immediate family (Humphrey & Symes, 2011).

The social communication difficulties characteristic of autism also impact the parent-child relationship and in turn, parental well-being. Typically, parent-child interactions are the earliest and primary source of social interactions; however, parents with autistic children identify social communication impairments as a major stressor when they are trying to understand or engage with their child (Hayes & Watson, 2013; Pastor-Cerezuola et al., 2016). The severity of problem behaviors and prosocial behaviors has been shown to predict parent stress levels (Pastor-Cerezuola et al., 2016; Shepherd et al., 2018). Studies suggest that autistic children use verbal communication primarily for behavior regulation (Shumway & Wetherby, 2009); therefore, social communication skills must be actively taught and practiced (McConachie & Diggle, 2005). The increase in autism diagnoses and research demonstrating the positive impact of intervention (Wetherby et al., 2004) for both child and parent well-being (McConachie & Diggle, 2005) suggests a need for interventions that are directed at, and actively involve, caregivers (Lord et al., 2005).

Parent-implemented social communication interventions for autistic children

There is growing evidence that supports the effectiveness of social communication interventions as early as possible for autistic children, preferably prior to, or by, the age of three and half (Pacia et al., 2022; Shumway & Wetherby, 2009). These interventions incorporate social communication strategies to support social skill development, which is considered one of the most effective practices for skill improvement (Waugh & Peskin, 2015). These interventions work to increase social understanding and develop social cognitive (e.g., theory of mind) and social communication skills (Cheung et al., 2018; Waugh & Peskin, 2015). Early intervention can promote the development of a foundation of social skills in autistic children, including: nonverbal communication (e.g., interpreting, following, and responding to nonverbal cues; intentional gestures), social awareness and reciprocity (Erturk et al., 2020; Zachor et al., 2007), verbal communication skills, shared social interest or enjoyment, and versatile interaction abilities across different contexts (e.g., play; Binns & Cardy, 2019; Oosterling et al., 2010).

The parent is currently regarded as the most powerful influence during early childhood; therefore, their inclusion and active participation within interventions is crucial (Oosterling et al., 2010; Shalev et al., 2020). The importance of parent inclusion has been acknowledged in programs such as Joint Attention, Symbolic Play and Engagement Regulation (JASPER; Kasari et al., 2015), Milton and Ethel Harris Research Initiative Treatment (MEHRIT; Casenhiser et al., 2011), and the Preschool Autism Communication Trial (PACT; Green et al., 2010) through parent-implemented components. Further, some interventions that include a naturalistic component, where programs are completed in natural environments to generalize skills, have also incorporated parent-mediation, such as Enhanced Milieu Teaching (EMT; Kaiser et al., 2000) and the Early Start Denver Model (ESDM; Contaldo et al., 2020; Rogers et al., 2021; Waddington et al., 2020). However, to date they typically do not include a component for parent well-being and support beyond strategies for their child's development. This is highlighted in a systematic review of parent experiences, which suggests interventions should include parent care and support (Jurek et al., 2023). Increasing parent-implemented programs with a focus on well-being is fundamental given parents spend the most amount of time with their child and therefore can support skills and strategies taught within an intervention across numerous contexts (Jurek et al., 2023; McConachie & Diggle, 2005; Shalev et al., 2020).

Accordingly, the American Academy of Pediatrics recommended that interventions for autistic children take a holistic approach, which includes increasing informational understanding for families, integrating natural environments, enrolling parents as active agents, and supporting

the well-being of the child's parents (Siller et al., 2013). The inclusion of all these recommended components is often difficult and this is reflected in the integration of some aspects, such as concurrent parent-only sessions (e.g., Frankel et al., 2010; Soorya et al., 2015) or a small number of parent sessions (e.g., de Bruin & Verheij, 2012), but not all. Further, parents are not usually the primary focus of social communication interventions for autistic children, therefore parent education and well-being are not typically emphasized (e.g., JASPER, MEHRIT, PACT, EMT; Casenhiser et al., 2011; Leadbitter et al., 2020; Waddington et al., 2021). This should be remedied given that parental responsiveness and parent-child synchrony (mutually regulated, reciprocal, and harmonious parent-child interactions) are related to social skills in autistic children (Haven et al., 2014). Notably, the extent to which the needs of parents are incorporated in interventions that take a holistic approach have not been investigated. This is essential given the high levels of parenting stress in this population and the negative influence this stress may have on the effectiveness of interventions (Osborne et al., 2008; Shalev et al., 2020). Therefore, research focusing on the parent perspective when it comes to holistic approaches is needed, not only to ascertain the parent-perceived benefits to the family, but also the parent's perception of the feasibility of attending and completing a program. Furthermore, given the parent focus in holistic interventions, the actual benefit to the parents needs to be understood as they are perceived by the parent. A holistic approach is incorporated within the components of TalkAbility™.

Talkability™

TalkAbility™ is a manualized, parent-implemented social communication intervention for verbal autistic children who are aged 4 to 7 years (Sussman, 2006). Developed by The Hanen Centre, TalkAbility™ is based on the social interactionist model of language acquisition (Gopnik & Meltzoff, 1998) and empirical research that shows that children learn best from their parents when interacting in natural and familiar contexts (Prizant & Wetherby, 1998). TalkAbility™ is designed to maximize the role that parents play in promoting their children's social cognitive functioning and social communication skills and reduce parent reliance on clinicians and other external services. It helps parents learn to create opportunities for, and take advantage of, everyday conversations and activities to support their child's conversational skills, social perspective taking, peer interactions, and other social cognitive skills (Sussman, 2006). TalkAbility™ incorporates a holistic approach and parents receive a guidebook outlining the program, *TalkAbility™: People Skills for Verbal Children on the Autism Spectrum – A Guide for Parents*, to use as a reference (outside of the intervention). The guidebook allows parents to review different aspects of the intervention, which increases the probability of retention of

taught strategies (Sussman, 2006). This is something not typically included in other parent-implemented interventions (e.g., JASPER, MEHRIT or PACT).

TalkAbility™ has two pre-program components not usually included in other interventions: (a) 2 hour group orientation and (b) 1.5 hour home visit where a TalkAbility™ trained speech-language pathologist assesses the child and parent-child interactions, and records parent-child interactions in a variety of contexts. This allows an informal evaluation of the child's communication skills in a natural context and provides a baseline of parent-child interactions.

The TalkAbility™ program consists of two main components. The first is comprised of eight 2.5 hour weekly (or biweekly as noted below) instructional group sessions where parents learn: (a) to target conversational goals; (b) strategies to help their child talk about abstract ideas (e.g., past/future, pretending) and promote pretend play; (c) about social perspective taking to support their child's perspective taking skills; (d) strategies to help their child understand nonverbal communication; (e) to apply social perspective taking to story-telling with their child; (f) to facilitate peer interaction and design a play date; (g) strategies for facilitating peer interaction; and (h) about social problem solving, how to help their child develop skills and strategies to solve their own social conflicts, and how to help their child celebrate positive behavior moments. Parents have homework each week to apply what they have learned to everyday interactions with their child. The group sessions allow parents to discuss learned concepts, their homework assignments, and engage in encouragement and support. The second component is comprised of three individual video feedback sessions for parents (between sessions 2 and 3; 5 and 6; 7 and 8). Parents are coached while they interact with their child to maximize opportunities for a positive interaction. This interaction is also reviewed in a subsequent group session so parents can share their successes, learn from each other in a supportive environment, and get or give feedback alongside other parents in the program. This promotes self-evaluation and continued use of taught strategies. This results in a total of 11 program sessions.

Although the TalkAbility™ intervention follows a sequence of sessions, it does not prohibit progression if the autistic child does not master a taught skill (like MEHRIT). Additionally, a major goal of the TalkAbility™ program, not typically incorporated in other interventions (e.g., Casenhiser et al., 2011; Green et al., 2010; Kasari et al., 2015), is to assist the parent in hosting playdates for their autistic child, which expands from a focus on parent-child social interactions to supporting parents in organized peer play groups in natural settings.

Current study

The goal of our study is to broaden our understanding of parent experiences regarding a holistic parent-implemented

social communication intervention, specifically the TalkAbility™ program, through a qualitative viewpoint. To gain an understanding of parent perspectives, we used an open-ended interview with questions regarding: (a) their concerns about their autistic child particularly with respect to social communication, (b) challenges with respect to the parental role, and (c) any benefits of TalkAbility™ on child social communication skills after completing it. Interviews were conducted with parents prior to, and following the completion of, TalkAbility™, as well as 6 months later to gain a full picture of the parent experience.

Method

Procedure

This study was approved by the university Research Ethics Board and The Hanen Centre, and was conducted in accordance with the ethical standards as outlined by the 1964 Declaration of Helsinki and its later amendments. The Hanen Centre is a charitable organization that specializes in interventions and support for families with children who have language problems. Parents on The Hanen Centre waitlist for TalkAbility™ were notified that a study was taking place in conjunction with the offering of the program. At the pre-program orientation, research personnel provided parents with detailed information regarding the study, handed out the information letter/consent forms, and answered any questions that parents had about the research. Parents interested in participating contacted researchers and provided their informed written consent to take part. All participating parents were interviewed at three time points: (a) pre-program, (b) post-program, and (c) 6-month follow-up.

Participants

In total, 11 mixed-sex two-parent families of an autistic child (confirmed by parent report) took part in the pre-program interview. Scheduling issues and families moving out of district resulted in three families not doing the post-program interview and one family not doing the 6-month follow-up. Family health issues resulted in another family not completing the post-program interview. This resulted in seven participants at the post-program and six at the 6-month follow-up timepoints. A comparison of family characteristics showed no differences between families who remained in the study and those who dropped out (see section “Background Characteristics” below). Similarly, qualitative analysis of responses from participants who completed all timepoints and those who dropped out showed no differences in codes or themes and data saturation was achieved with the six participants who completed all timepoints, with no additional codes

evident in the participants with missing data. Therefore, participants who completed all timepoints ($n=6$) were included in the current analysis.

Parent interview. The interview was created to assess parent perceptions of their experience in the TalkAbility™ program, as well as their broader experiences with their autistic child and available supports and services. This interview was conducted by trained graduate students and took between 30 and 60 minutes. The interviewers had no vested interest in the intervention that might bias the responses provided from the interview and were not involved in any subsequent data analysis or interpretation and dissemination of results.

The first author, in consultation with the executive director of The Hanen Centre, created the parent interview to understand parent perception of the TalkAbility™ program, including how they felt about the program, what they took away from the program, and their beliefs regarding any associations between completing the program and their child’s social behavior. It was comprised of two main parts: (a) a structured interview that asked about family demographics, parenting experiences, services and support accessed for their child, and background regarding the child’s development, health, behavior, academics, interests, relationships, and personality and (b) an open-ended interview that included general questions about the child’s communication capabilities and difficulties, and the parent’s thoughts regarding their child and their child’s communication challenges and the TalkAbility™ program. All interviews were audio recorded, transcribed verbatim, and double-checked for accuracy.

Background characteristics

The included and dropped out families were comparable with respect to interviewee (primarily mothers), family composition (two-parent), full-time employment of at least one parent, sex of autistic child (primarily males), average age of autistic child (4.49 years, see table 1). In all the families, the first language of the autistic child was English; one family reported their household language included Spanish and another Tagalog. However, English was spoken exclusively with their autistic child. The number and age of siblings ranged from 0 to 4 years and between 5 months and 32 years, respectively, in the included families, and 0 to 4 and between 4 months and 18 years, respectively, in the dropped out families.

Qualitative data analysis

Parent interviews were analyzed according to Braun and Clarke’s model of thematic analysis (Howitt, 2016). The first and second author created a code manual for all interviews using a data-led approach and review. Within the

Table 1. Background characteristics of families who participated at each time point.

	Pre- and post-program and follow-up	Pre-program only	Pre- and post-program only
Sample size	6	4	1
Interviewee (n) Mother:Father:Both	4:1:1	3:1:0	0:0:1
Two-parent families (%)	100%	100%	100%
Full-time employment (at least one parent)	100%	100%	100%
Sex of autistic child (Boy:Girl)	4:2	3:1	1:0
Average age of autistic child at pre-program timepoint (years)	4.91	4.75	4.00

structured interview four sections were considered for qualitative analysis: (a) child development and behavior, (b) school, interests, relationship and personality, (c) parenting experience, and (d) child services and support. The first author verified coding reliability and consensus was attained on all codes and themes. The second author (who was the primary coder) completed a reflective piece pertaining to any influence the researchers may have on the qualitative process; this was reviewed by the first author and no conflicts that may have influenced coding were identified. All interviews were recoded, using the code manual, a minimum of 6 weeks following the initial coding to ensure reliability and accuracy of the initial coding. Data saturation was met ($n=6$) following the coding process. Subsequently, all codes were amalgamated into representative themes inclusive of the entire interview.

Trustworthiness and rigour

Following the recommendation of employing a minimum of two methods of rigour within qualitative research (Amin et al., 2020), we engaged in persistent observation (Korstejens & Moser, 2018), negative case analysis, investigator triangulation, and reflexivity to ensure the scientific rigour of the current study (Lincoln & Guba, 1986). Specifically, the data were continually reviewed throughout the analysis process to ensure familiarity. Multiple investigators across different disciplines were involved in the process of data collection and analysis, which allowed different perspectives. The use of negative case analysis allows for all data, inclusive of those that did not align with the developed themes, to be explored and discussed, which results in a more thorough understanding and fairness of the data (Amin et al., 2020). Finally, reflexivity was employed so that the researchers consistently reflected on pre-conceptions or influences on the data that were jointly discussed.

Qualitative results

After completing the thematic content analysis, codes were organized into four key themes inclusive of all time-points that represented parent statements regarding the

TalkAbility™ program: (a) child communication difficulties and parent frustrations, (b) child social relationships and parent concerns, (c) parent discussed communication strategies, and (d) thoughts and emotions surrounding TalkAbility™.

Theme one: child communication difficulties and progress and parent frustrations. Prior to TalkAbility™, parents indicated their autistic child had significant difficulty with expressive language (e.g., finding words for emotions, starting conversations), receptive language (e.g., meaning of words), understanding of social interactions (e.g., social timing, topic changes), nonverbal language, and facial expression comprehension. Parents reported that the culmination of many of these issues resulted in difficulties engaging in and maintaining conversations with their child. After the intervention, child understanding of nonverbal cues (e.g., facial expressions), parent understanding of child verbalizations, and their child's ability to follow conversation (e.g., topic changes) were no longer noted as communication difficulties by parents. Parents did not express as many receptive and expressive communication difficulties at follow-up and the challenges parents mentioned seemed more advanced (e.g., social perspective taking, understanding emotions, and initiating conversations with strangers) than those described at the pre-program timepoint. This suggests the strategies learned by parents from the TalkAbility™ program may have an increasing positive influence on reported social communication skills in their autistic child over time. Although parents continued to discuss receptive and expressive language difficulties 6 months following the program, they highlighted skill progress as discussed by TAP003:

his biggest problem is his speech delay and [...] I think the way he processes the information where [...] he needs more time to think about his words and his sentences. It seems to me that that is getting much shorter, so he's able to make up longer sentences and he's starting to do [...] more social chit chat like 'oh nice dog' kind of stuff like that.

Further, following the program, parents demonstrated an understanding and acceptance of their child's communication

difficulties by conveying that some of them might stem from social anxiety. This was simply put by TAP002 who noted “[communication] with anyone outside of this house is very difficult for him.” The consequence of this social anxiety was further explained by TAP002 who said “he [...] [is] just really shy. So, he has a hard time just initiating conversation or even to ask to have a turn or if he can play.”

Parents discussed communication refusal and associated parental frustration at all timepoints; however, they were stated more often before the program than after. Descriptions of communication refusal included negative emotions (e.g., anger) to avoid communication bids from the parent. This was conveyed as a key area of frustration for parents as they felt tuned out, ignored, and helpless in their repeated attempts to garner their child’s attention. Following the intervention, communication refusal and the associated frustration were only mentioned when associated with times of heightened negative emotion including anger, fear, or discomfort (e.g., around strangers). This suggests progressive improvement and/or confidence in parent management of their child’s communication refusal in daily situations, with only extreme examples being perceived as relevant to discuss; however, studies looking at the efficacy of this program on reported child difficulties is necessary.

An additional area of frustration for parents was their autistic child’s challenges around social perspective taking. Prior to the program, parents found it difficult to teach their child how to understand that others have perspectives, thoughts, and emotions that may differ from their own prior. This was discussed by TAP011 who stated:

it’s [...] the level of awareness that [...] is frustrating because [...] there are a lot of concepts that she doesn’t understand and [...] it’s frustrating because you would expect her to, but at the same time I [...] try not to have high expectations because I don’t know what goes on in her head. So, she still doesn’t understand that hey if you made mommy angry you can’t laugh about it, so she still doesn’t understand what that means.

After the program, only one parent reported continued difficulty in this area, which may reflect the decrease in concern by most parents after TalkAbility™; this needs to be confirmed with future investigations using appropriate quantitative methods.

Theme two: social relationships and concerns. Social relationships were discussed in-depth at all timepoints, however the nature of the concern as well as progress in these relationships differed across timepoints. Numerous topics were brought up within this theme, including the parent–child relationship and feelings of closeness versus distance within that relationship, perceived parent responsibilities, child’s friendships, and both negative and positive social behaviors.

Parent feelings regarding closeness with their autistic child remained consistent across timepoints, with the evening and bedtime routine identified as a time of closeness due to the calm demeanor of the child and the quiet environment. At follow-up some parents also included instances of joint play as a time of closeness. Close and calm interactions were not perceived as possible during the day by most parents across timepoints due to the child’s emotional state (e.g., tired, excitable, cranky) and associated behaviors (e.g., temper tantrum). Parents reported distress during these times because their child’s emotional state and negative behavior hindered positive communication. As described by TAP009, the parent felt distant when the child was “in his own little world” and not communicative, which was reiterated by TAP011, who got “frustrated” and would “just give up sometimes” when the child refused to listen or engage in communication. Aggression was noted prior to the intervention; TAP011 stated that when their autistic child became angry “she would hit me and honestly that [...] hurts me a lot [...] emotionally not physically, [...] and I always [...] repeat over and over again ‘[child] you cannot hit mommy, you cannot hit anybody, no that’s wrong but it keeps happening.’” Though many parents reported episodes of aggression, none said their autistic child was aggressive. Following TalkAbility™ the parent–child bond was perceived to strengthen as explained by TAP009 who said that “now that he’s maturing more I would say that the bond is a little stronger, especially with [father] and [child]”. Directly following TalkAbility™, most parents reported that aggression within social interactions did not occur. At the 6-month follow-up, parents reported observing fewer behavioral outbursts, which resulted in fewer conflicts that were associated with parental frustration or stress.

Prior to TalkAbility™, parents indicated a perceived responsibility to learn and understand their child’s diagnosis. This feeling was discussed by TAP003 who said her husband experienced feelings of guilt that he did not gain sufficient knowledge about autism following their child’s diagnosis, resulting in the mother having “the instruction manual and he doesn’t.” This concern was particularly evident when it came to knowledge about expectations for age-appropriate social communication. This differed at follow-up as parents expressed that they did not feel as much need to be an interpreter or facilitator for their child. Parents reported that this resulted in conflicted emotions, pride in their child’s progress and resulting independence, but sadness at being needed less.

Prior to TalkAbility™ many parents reported concerns about the number of friendships that their autistic child had. Some indicated their child had up to five friends, but most said two or none at all, which resulted in those parents being worried that their autistic child experienced social isolation. This fostered worry that their child’s reluctance to socialize would damage or prohibit the formation

of friendships and social play even with parent facilitation. Although these concerns were maintained post-program, at the 6-month follow-up, parents indicated that their autistic child was able to engage in joint play (where the child engages in play behaviors with another child or adult partners; Marwick et al., 2022) without significant intervention or interpretation from the parent. In fact, parents reported that their autistic child now experienced mature friendships with more friends (a minimum of four outside of the family) and communicated within these friendships. In addition, most parents noted that it was easier for their autistic child to initiate friendships and that it happened faster—“that was her first interaction in a [...] typical classroom with typically developing kids and she immediately made a best-friend so that was a huge thing...” (TAP011)—demonstrating their child’s independence and self-confidence in using social communication skills to initiate and maintain social relationships. Further, following TalkAbility™ parents indicated that they organized more play dates between their autistic child and peers. Parents described progress in their autistic child’s social play (e.g., comfortably engaging in imaginative play with friends) and reported having less concern about the play roles their child was assigned (e.g., villain). This was also reported by parents 6 months later. Before the program some parents indicated they were their autistic child’s best friend; however, at the 6-month follow-up they reported their autistic child had a consistent or current best friend, and all parents said their autistic child discussed “favorite classmates,” friends, or best friends from school. Furthermore, their child’s emotional understanding within these social relationships reportedly improved following TalkAbility™; parents felt their child was capable of understanding and engaging in empathy.

Theme three: communication strategies. Prior to TalkAbility™, parents said they tried self-education to learn about language skills and communication strategies to help their autistic child (e.g., give child space and time to assess the social environment before stepping in to help with explanations). Parents reported using the strategy of repetition of information to help increase comprehension pre-program, especially when a child was exposed to new activities. Although self-education was emphasized pre-program, it was omitted during the post-program interview. Instead, parents seemed more confident and knowledgeable about using strategies in different situations. Further, at follow-up, parents discussed how they conducted “mock trials” of social interactions at home as teaching aids for their autistic child which goes beyond any social practice prior to TalkAbility™.

Following TalkAbility™ parents discussed their ability to use patience and take advantage of naturalistic opportunities to implement strategies with their child. This was discussed by TAP007; “we’re just constantly using

opportunism, like dinner or play or routine to reinforce pieces of conversation [...] and praising positively when he does demonstrate something that we’re working on.” In addition, after completing TalkAbility™, parents valued the development of their autistic child’s communication skills over how others might perceive their child. As a result, when their autistic child was interacting with others and needed help, parents made sure that those engaging in the social interactions allowed their autistic child to finish their thought and be an active part of the conversation. These strategies were expressed by TAP007:

We’re not peppering with questions, we’re [...] asking, [...] we’ve stopped caring as much about polite interaction with family members, it’s like wait, okay [child] go ahead [...] that kind of thing; he needs some time. So [...] I think that’s been the biggest take away for me is [...] patience, waiting and then [...] being a little more patient in terms of introducing our own ideas and just [...] picking our [...] spots ...”

Prior to TalkAbility™, planning as a strategy included giving their child expectations regarding the social outing in a step-by-step manner. This strategy was exemplified by TAP005 who gave their autistic child “... fair warning, [...] in five minutes we’re gonna go to this person’s house and this is what is expected of you and what we’re going to do.” After completing TalkAbility™, parents indicated that the planning strategy changed slightly and it was discussed in terms of informing the child of a step-by-step plan of the social event or interaction so the child would be prepared and nothing would be a surprise. This was expressed by TAP002:

we talk about it beforehand, [...] before we go to school or before we go somewhere. We explain that there are people and you don’t need to be afraid [...] if we were let’s say, going [...] up to the cottage and there could be other people there, like other family members and it’s not just immediate, like uncles and aunts and cousins, we’d have to explain that we’re going there and other people are going to be there, [...] and it’s [...] okay if you don’t talk to they, they’re just gonna say hi, they’re nice people.

As part of this strategy, parents made plans to remove their child from the situation if they experienced discomfort or anxiety. This planning strategy was reiterated 6 months after program completion as a valuable communication strategy that increased their autistic child’s comfort with social interactions, and in turn, promoted increased social communication.

After learning about social stories in the TalkAbility™ program, parents discussed using books and social stories as a strategy to increase social understanding and improve

social communication skills and perspective taking. This was exemplified by TAP011 who stated: “I read a lot of stories for her about [...] feelings, [...] and how, when people feel angry, when people feel shy, when people feel jealous.” The strategy of using social stories to help their autistic child understand their own emotions, and to realize others may hold different emotions and perspectives was reiterated by other parents. Another strategy discussed as learned through the TalkAbility™ program was the use of imaginative play to increase emotional understanding and differing perspectives. This was exemplified by TAP007 who stated they used “imaginative play a lot, [...] cause he’s very keen on pretending and pretend play, so [...] introducing our own ideas, insisting in [...] those kind of things, [...] we’ve been doing that a lot [...] through play, I think that’s been a big take away from the [...] [TalkAbility™] sessions.”

Theme four: thoughts and emotions surrounding TalkAbility™.

Prior to the TalkAbility™ program parents voiced feelings of hope (e.g., regarding potential program benefits for their autistic child’s social communication) and relief (e.g., because of previous difficulty accessing social skills interventions). Excitement also stemmed from the components of the course (e.g., specific social communication, peer integration strategies) and opportunity for learning, as well the potential for communication skill development. This excitement was expressed by TAP001:

“[Child’s] heading into grade one so I think it’s a really good time [...] to work what we can from the program [...] and build him up for some success in the first grade”, followed by “I’m excited [...] it’s [...] a course specifically geared to kids with trouble with social communication so I think that [...] we’ll probably find some commonality with the other parents in terms of identifying what struggles we have”.

Directly following TalkAbility™, parent reflections were positive; for example, “it was wonderful” (TAP003), and “I loved it [...] very helpful” (TAP005). Parents reported that the program surpassed expectations they held based on past interventions they had participated in for their autistic child. Further, 6 months following completion, parents reported a changed mindset, which ranged from acceptance of their child’s autism diagnosis to empowerment in their ability to help their child’s development and social skill. The TalkAbility™ intervention was perceived as empowering because parents learned a large repertoire of strategies to use across numerous situations. This was expressed eloquently by TAP003:

I think it was very empowering for me as a mom and I [...] feel like [...] the [...] resources and the tools that I got from [...] TalkAbility were [...] very useful and [...] what we

needed to [...] continue to improve our level of communication [...] before doing the course I felt very burdened [...] because my idea was that he had to learn to say his sentences in order to express himself the right way, and after the course I [...] learned that that’s not gonna happen unless I start meeting him somewhere in the middle.

This adjusted perspective was noted by another participant who discussed recognizing the need to accept their role as a parent without taking on the full responsibility of a therapist. This was conveyed by TAP003 as “before the program I was behaving more like [...] a therapist [...] after the program I realized that my role was not therapy [...] I’m a mom and so I have a more intimate relationship with my kid and I know him better.” This highlights the feelings of responsibility and pressure some of the parents experienced trying to raise their autistic child and the benefits of the TalkAbility™ program on changing parental identities.

The ability to learn and incorporate strategies with flexibility, including using strategies depending on their child’s needs and moving forward to learn subsequent lessons without mastering previous strategies, was a welcomed perceived difference between TalkAbility™ and other interventions parents had been part of. Parents reported that the flexibility of TalkAbility™ strategies allowed them to be tailored to their child’s needs and daily interactions. The incorporation of structured and free play strategies in different contexts (e.g., home, school) and with different playmates (e.g., siblings, peers) was noted as a positive inclusion that parents liked. Further, the strategies included in TalkAbility™ were described as relevant to daily life (e.g., *hook to get looks* strategy). Parent comments regarding the perceived flexibility and longevity of the strategies taught in the TalkAbility™ intervention needs to be objectively measured in future research. Parents also welcomed learning how to plan and facilitate play groups that would benefit the social skill development of their autistic child, which continued to be positively reviewed 6 months later as reported by TAP002:

A few little techniques [...] when it comes to [...] playdates and planning playdates and watch and how kids play [...] how you structured time and free time and [...] things can move very quickly and not to set high expectations and things like that.

The importance of story-telling and books was often a new lesson for parents as a result of the program, one they felt was useful and easy to incorporate in their daily routines. Although some parents mentioned reading books for entertainment, their educational value was not previously understood; after TalkAbility™ they “pick [...] books differently because I learned that there’s some stories that are more about pretend or more about feelings [...] and that actually

helps.” These strategies appeared to shift parents’ perspectives regarding their child’s difficulties and diagnosis, encouraging them to embrace their child’s learning curve, which differs from the developmental expectations and skill acquisition of typically developing children, and encourage growth in their child’s social communication skills. Additionally, parents deemed the group discussion component facilitated by the speech-language pathologist as very beneficial because they allowed parents to create sustainable networks with each other that allowed the sharing of positive and negative parenting experiences. Parents continued to appreciate this component 6 months following TalkAbility™, as discussed by TAP010: “it was also sort of the parent network that was there, cause a lot of us are like oh yeah you know I’ve been through that too and I’ve tried this or I’ve tried that, like that support was very very helpful.” This demonstrates the support parents felt when given the opportunity to discuss their home lives and experiences with others who may have similar experiences with an autistic child.

Parents endorsed the method of teaching, specificity of strategies, and intervention components. The method of teaching, which incorporated division of information into manageable and understandable units was noted as particularly helpful by TAP007: “I really liked how the sessions were divided up, I think they were chunked very appropriately.” The video sessions were also positively discussed by participants as it enabled parents to “see progress” and facilitated active teaching by the speech-language pathologist who was described as “great at finding [...] the little details from his communication or his attitudes [...] so it was great to learn from those little moments and understand that the little pieces are there we just have to [...] work on them” (TAP003). The video component seemed to help parents understand their child’s and their own strengths and weaknesses when communicating with each other. Parents felt the TalkAbility™ strategies continued to be relevant 6 months after completing the program and they were confident about using them in the home because they could refer to the provided guidebook.

Discussion

This is the first known study to qualitatively examine interviews from parents of an autistic child regarding their perceptions of a holistic parent-implemented social communication intervention (TalkAbility™) before and after program completion. As such, the current study is intended to be a preliminary investigation that helps direct quantitative research regarding TalkAbility™ as well as other parent-implemented programs. We coded parent responses to identify main concerns regarding child social communication skills and challenges with respect to the parental role, as well as review parent perceptions of the TalkAbility™ program. Parents report they had fewer concerns regarding child

communication difficulties and parenting challenges after the program, and numerous benefits of TalkAbility™. Importantly, although parent experiences are of value, the current study also identifies areas that require further investigation in addition to, and beyond, parent perceptions of this program.

Concerns regarding social communication skills

Parents reported that their autistic child’s social communication skills improved directly following the TalkAbility™ program and that they were partially maintained at the 6-month follow-up. Notably, parents described more complex social communication challenges at follow-up (e.g., perspective taking, emotion comprehension). This differentiation in basic versus complex social communication challenges after the intervention and 6 months later is important because it reflects a more sophisticated understanding of skill progress in their autistic child. The longitudinal aspect of the current study allows insight into parent perceptions of progress in social communication skills in their autistic children that were attributed to the TalkAbility™ intervention, which has not previously been investigated. These results expand those from previous studies that show parent reported improvements in their child’s social communication skills directly following a parent-implemented intervention (PACT, JASPER, MEHRIT; Casenhiser et al., 2011; Green et al., 2010; Kasari et al., 2015). Another important finding in the current study, across all timepoints, is the parent-perceived negative impact of heightened emotions on social communication in their autistic child. This suggests that current interventions may benefit from including social communication strategies for parents in situations where their autistic child is experiencing heightened emotions. Additionally, communication refusal (e.g., ignoring, tuning out) was reported in some capacity at all timepoints. This highlights parent feelings of difficulty with effectively eliciting responses from their autistic child during times of communication refusal and a need for strategies that specifically target this type of situation.

Developing and maintaining social relationships was a noted concern by parents, but this changed following the TalkAbility™ intervention. Parents reported not only a growing number of friendships their autistic child formed and maintained, but also their child’s use of positive social behaviors and skills within these friendships. Parents felt that the TalkAbility™ intervention taught them strategies to encourage social communication skill development and provided tools to facilitate increased social behavior in their autistic child. Previously studied social skills interventions for autistic children are either peer-mediated with minimal incorporation of parents (e.g., parent acts as interpreter for child in some peer-mediated interventions; Peer Network Interventions, Peer Tutoring Approach, Integrated Play Groups) or are parent-

mediated with no play facilitation with peers (e.g., JASPER, MEHRIT, PACT). Although the JASPER intervention (Kasari et al., 2015) teaches parents play facilitation strategies when playing with their child, it does not include organized peer play dates, which are part of TalkAbility™. In the current study, parents reported this aspect as being beneficial; this indicates the inclusion of organized peer play dates in a natural social context may be a useful addition across interventions. Additionally, parents highlighted the benefits of explicit instructions (e.g., *hook to get looks*) to facilitate and encourage social communication in their autistic child in social environments (e.g., school, parks, playdates). These methods are perceived as valuable by parents but require further investigation to assess their efficacy in the skills and behaviors of autistic children.

Challenges regarding the parental role

Though parents are acknowledged as a critical aspect of social skills interventions for autistic children (Oosterling et al., 2010), the challenges and frustrations that they experience regarding their child's social communication have not been explored following interventions. We find that the parent-reported quantity and quality of frustrations at post-program and follow-up are fewer than at the pre-program interview. Previous studies have shown that parenting stress is attributed to social communication problems in their autistic child (e.g., Shepherd et al., 2018); furthering the literature, the current study shows that from the pre- and post-program interviews, parent frustrations were attributed to specific social communication difficulties their child was exhibiting. The pre- and post-program data suggest a relation between child communication difficulties and parent frustrations. That is, frustrations that parents no longer discussed at the post-intervention timepoint may reflect progress in these omitted difficulties in the social communication skills of their autistic child. The current study examined the lived experiences of parents prior to and following a parent-implemented social communication intervention, which allowed the relation between social communication difficulties and parent frustrations to be voiced. This relation should be explored quantitatively to guide modifications or adaptations to interventions that incorporate different aspects of the parent-child relationship and the specific communication difficulties associated with these aspects. Further, parent perceptions regarding challenges or difficulties engaging in a program should be more explicitly investigated to ensure social communication interventions are accessible to all families.

Clinical implications

In the current study, parents had the opportunity to voice their thoughts about TalkAbility™. As the only parent-implemented social communication intervention to

include a complete holistic approach, that we are aware of, the detailed reports provided by the parents in the current study demonstrate the positive perceived value of the components in a holistic approach. Though the consistent positive overall reviews of TalkAbility™ speak to parent satisfaction, the positive comments and constructive feedback regarding specific components of the program are most useful. Knowing the intervention aspects that parents view as specifically valuable allows targeted modifications that reflect actual parent needs. In the current study, the specific components that were positively reviewed by parents include the guidebook, video sessions and feedback, social stories and play strategies, and discussions amongst the parents at the different sessions, which are reflective of the holistic approach.

The guidebook provided by TalkAbility™ was used by parents post-program to review strategies or information that was applicable to behaviors that parents continued to observe in their children. Being able to refer to the guidebook seemed to increase parental confidence regarding their ability to use learned strategies when needed. This extends previous research investigating parental self-efficacy and implementation of intervention strategies; the parent's ability to implement strategies that were specifically applicable to a child's behavior were instrumental in the perceived relevance of an intervention (Russell & Ingersoll, 2021). As such, a parent guidebook is a simple, but potentially powerful, addition to any parent-implemented intervention. In the current study, video sessions and feedback allowed parents to visually review interactions with their child and receive personalized feedback that was considered directly relevant and useful for future interactions. This feedback is similar to the positive parent views of the video feedback provided in the PACT-G intervention (Carruthers et al., 2023), suggesting this component is a beneficial inclusion across different interventions. Integration of personalized video feedback regarding parent-child interactions may be more influential and more likely to be remembered than the use of general examples.

Although play strategies are often included in parent-mediated social skills interventions, few incorporate social stories. Social stories provided parents in the current study with a tangible method of teaching emotions and perspective-taking skills to their children that they felt confident implementing. Of note is that parents in the current study specifically highlighted the inter-parent group discussions as having an unexpected psychological benefit. This finding points to the need for parent support networks and open group discussions within interventions. Incorporating parent support networks within an intervention could contribute to decreased parenting stress and increased parental empowerment and confidence to continue implementing taught strategies in the home, which further benefits their child's development (Leadbitter et al., 2020). Higher levels of parenting stress are associated

with reduced quality of parenting (May et al., 2015), which may negatively impact the parent's ability to implement strategies and encourage social communication development in their autistic child. Thus, intervention components that target parenting stress are important to consider.

Limitations and future directions

This is the first known qualitative study to incorporate a 6-month follow-up to investigate parent perceptions regarding a holistic parent-implemented social communication intervention. The current study permitted an in-depth understanding of parent views and lived experiences following a social communication intervention for their autistic child. We find that parent reports demonstrate not only a positive view of the program but continued use of learned strategies and positive comments regarding their autistic child. We acknowledge however, that our questions were open-ended and did not prompt specifically for less positive aspects of the program. Therefore, parents may have focused on positive perceptions and omitted negative views. At the same time, anecdotal reports from parents of autistic children indicate a great desire for any program due to the significant lack of available programming for their children. It is possible that this desire is reflected in the lack of less positive comments. Regardless, questions that specifically prompt for both perceived positive and negative reflections of a program would help our understanding of parent views regarding difficulties associated with program components.

Replication is necessary given the rate of attrition in the current study, which was conducted prior to the norm of video communications that accompanied the COVID-19 pandemic. This speaks to the benefits of incorporating technology to decrease attrition in longitudinal studies, which can be a significant issue (Steinhausen et al., 2020). We recognize that not only could the experiences differ between families who drop out of longitudinal research versus those who complete them, but also that the experiences of our sample of parents, which was small, could be specific to them. Additional research is needed with a larger and more diverse sample to increase our understanding of parental needs; these could include views and themes that are different from the sample in the current study. This would expand our knowledge of the components that should be included not only in TalkAbility™ but any holistic program for autistic children. Long term follow-up studies that take a mixed-methods approach are also required to investigate the efficacy of holistic parent-implemented social communication interventions and extend our findings.

Follow-up studies are critical to understanding: (a) maintenance of intervention strategies by parents, (b) long term influence of intervention on child communication skills, (c) length of impact of intervention on social relationships, (d) benefits of intervention on parent well-being and the

parent-child relationship, and (e) parent experienced and perceived challenges and difficulties associated with participating in parent-implemented social communication interventions. The current study demonstrates the value of a qualitative analysis of social communication interventions; however, we relied on a parent (primarily mother) perspective. Other perspectives (e.g., siblings, other family members, teachers) may offer additional valuable information and understanding. Further, although qualitative analysis provides rich data, the incorporation of a mixed methods approach would allow objective pre- and post-program assessment of the autistic child's social communication skills and the parent's stress and frustration. Inclusion of standardized measures to provide objective data regarding social communication progress in addition to qualitative perspectives is critical prior to changing or modifying any existing program. Objective quantitative reports on both parent experienced challenges and child difficulties, as well as the potential relation between the two are necessary using a larger sample. It should be noted that the time between diagnosis of autism and entrance into the TalkAbility™ program was unknown. Therefore, parents may still be in the process of understanding their child's diagnosis. The level of parent acceptance and understanding of an autism diagnosis may influence both their relationship with their autistic child, as well as ability to understand and implement skills and strategies taught in any intervention.

Conclusion

We find that parents expressed a very positive review of a holistic parent-implemented social communication intervention (TalkAbility™). Parents report that many components of a holistic approach are instrumental in encouraging social communication in their autistic child. The current study provides a preliminary understanding of the critical components of a successful holistic parent-implemented social communication intervention, as viewed by parents. Further understanding regarding the influence of holistic parent-implemented social communication interventions on child communication skills, parenting frustrations, and parent-child relationships is needed. Results from this study demonstrate the critical importance of parent involvement in social communication interventions for autistic children and obtaining detailed parent feedback regarding the benefits of a holistic approach.

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Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical Standards

This study was approved by the Trent University Research Ethics Board and The Hanen Centre, and was conducted in accordance with the ethical standards as outlined by the 1964 Declaration of Helsinki and its later amendments. All participants provided written informed consent prior to taking part in the study.

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