

Supporting Self-Management for Autism Spectrum Disorder through Telehealth

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Abstract

Autism spectrum disorder (ASD) is a complex chronic condition, impacting the individual and their family, as they require life-long care starting at an early age. Self-management assists these individuals transition to adulthood without needing continued systematic support externally. Telehealth reduces the challenges these families experience when accessing self-management programs. However, current research on telehealth programs in this context are often aimed at early childhood or utilize a deficit-based approach to care, therefore fails to capture all aspects of self-management. This study employed a case-study approach to investigate how a clinically adopted telehealth program supports comprehensive self-management of autism. The results demonstrate the program provided self-management support through three processes: focusing on illness needs, activating resources and living with a chronic condition. The paper suggests further improvements are needed to achieve intended healthcare outcomes for the child and their families.

Keywords: Autism, self-management, telehealth, telemedicine.

1. Introduction

Chronic disease is taking a significant and increasing toll on lives with a rapid increase in chronic conditions, persistent or long-term health conditions (WHO, 2002; Adler-Waxman, 2017). Autism spectrum disorder (ASD), commonly referred to as “autism”, is an example of a chronic neurodevelopmental condition with 1% of the world population diagnosed with the condition (Zeidan et al., 2022). ASD encompasses a range of early-appearing social communication deficits and repetitive sensory-motor behaviors (Lord et al., 2018).

Autism is a lifelong condition starting from birth, and these individuals find it difficult to transition into adulthood, because they have limited capacity for

independent performance. They often rely heavily on their families and professionals to support them through the transition by means of systematic long-term instructions (Buckmann, 2000). To reduce their dependency on the family and health system, it is important to help individuals with ASD learn functional skills that increase their independence and help them manage their own condition and behavior. Their care needs to be accompanied by actions at community and societal levels for greater accessibility, inclusivity, and support.

Compared to other chronic conditions, autism is a more complex condition that not only impacts the individuals but also their families. The parents of autistic children are not only challenged by the condition itself, but also co-occurring medical concerns, developmental disabilities, and emotional or behavioral conditions (Parker & Killian, 2020). Besides the child’s symptom severity itself, the parents’ well-being is further influenced by social isolation associated with autism, the child’s need for specific and acute care, and the additional financial burden of on-going care (Parker & Killian, 2020). The increased demand on the caregivers and family leads to further physical, emotional, psychological and financial pressures (DePape & Lindsay, 2015). As autism is a life-long condition starting from birth, it is important that these individuals learn to monitor and adjust their own behaviors in a social situation without systematic support from others (Marshall & Rohrer, 2023; Neitzel & Busick, 2009). This helps lessen the pressure not only on their families but also on the healthcare system (Hakobyan & Harutyunyan, 2021).

Self-management offers a greater level of independence to individuals and can lessen life-long reliance on parents or healthcare professionals (WHO, 2002). Self-management aims to improve a wide array of skills such as social, academic skills, independent living and vocational skills and decrease challenging behaviors for autistic individuals (Marshall & Rohrer, 2023). Comprehensive programs for self-management should support several tasks based on the three

categories of self-management processes focusing on health needs, activating resources, and living with a chronic condition (Schulman-Green et al., 2012).

Individuals and caregivers experience many challenges when attempting to access self-management programs. Poor communication with healthcare providers and their reluctance to provide relevant information about the condition leads to parents/caregivers not being aware of self-management programs (DePape & Lindsay, 2015; Hakobyan & Harutyunyan, 2021). The lack of funding to access support programs and having to travel great distances to access the programs further demotivate the parents (DePape & Lindsay, 2015). In addition, often specialist services are inaccessible due to long waiting times, few proactive specialists and the multiple steps involved to access the services (Pasco, 2016; Rhoades et al., 2007).

Telehealth has the potential to offer a safe alternative mode of delivery for self-management programs for chronic conditions such as ASD (Hanlon et al., 2017). Telehealth is the use of information and communication technologies to deliver medical and non-physician services at a distance. For patients with chronic conditions such as ASD, telehealth can improve access to those restricted by geographical or mobility constraints, provide more frequent encounters with a care provider, reduce the need to travel and lower the risk of contracting other diseases (Stowe & Harding, 2010). Telehealth also supports caregiver participation in support programs and subsequent skill acquisition and behavior management strategies implementation (Nohelty et al., 2021). Telehealth programs for ASD self-management facilitate education, skills training, anxiety therapy, behavior analysis and occupational therapy (Domínguez-Lucio et al., 2023; Ellison et al., 2021; Ferguson et al., 2019; Kane & DeBar, 2023; Lamash et al., 2023; de Nocker & Toolan, 2023; Sutherland et al., 2018).

Current research on telehealth programs for ASD often do not take a holistic approach to understanding self-management. They mainly target a specific aspect of self-management, such as education about the condition or communication skills training, which is a narrow view of self-management activities. Therefore, there is a need for programs that adopt a comprehensive, holistic approach to self-management tasks and provide autistic individuals the skills and resources they require, customized to their own strengths.

This study focuses on a telehealth program that takes a comprehensive and strength-based approach to self-management. The telehealth program includes 8 interactive live sessions, offline activities, and

continuous engagement support through social media. The program is delivered via Zoom to parents helping to progress the child's goals by engaging their families. To better understand the elements of a holistic self-management program, the aim of this study is to investigate how well an established, clinically adopted telehealth program supports self-management of autism from the perspective of the parents. The rest of this paper overviews the current literature on self-management of autism, presents the methodology and the findings, and concludes with a discussion of the findings..

2. Literature Review

2.1. A framework for Self-Management

Managing chronic conditions such as ASD, is important to reduce the additional pressure on already stretched health care systems (Adler-Waxman, 2017). The Chronic Care Model (CCM) is a framework that was developed to improve the management and care of chronic diseases.

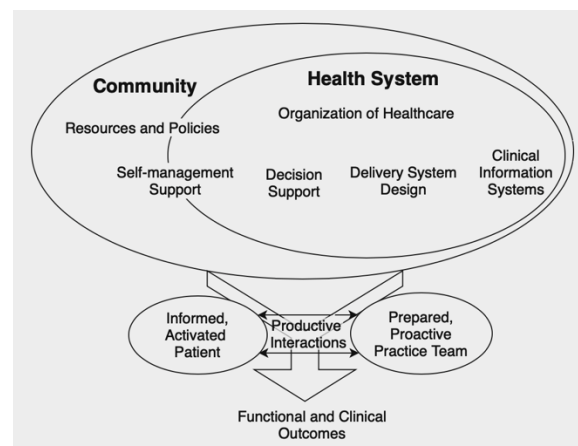


Figure 1. The chronic care model (CCM) (Wagner 1998).

The chronic care model (Wagner,1998) provides a framework for patient empowerment, self-management support, and enhancing clinical and behavioral outcomes (Gee et al., 2015). The CCM consists of six key components in a healthcare service/system that encourage patient empowerment, self-management support, and improving clinical and behavioral outcomes (Fig.1). Self-management support is an integral component of the chronic care model and is an essential element to create a healthcare system that manages chronic disease proactively. (Barr et al., 2003). The healthcare providers integrate self-management support activities with the other 5

areas of focus to create a personalized care process for their chronic patients, and thereby manage chronic disease proactively (Coleman et al., 2009).

2.2. Self-Management Processes

Self-management strategies assist individuals with chronic conditions such as ASD, achieve greater levels of independence (Buckmann, 2000; WHO, 2002). Using self-management strategies, individuals with autism can learn to regulate their own behaviors and act appropriately in community-based situations without direct intervention (Marshall & Rohrer, 2023; Neitzel & Busick, 2009). In their conceptualization of self-management for chronic conditions, Schulman-Green et al. (2012) identified activities that patients need to accomplish within each process which encompass the self-management experience used to guide the development of self-management programs and improve health outcomes (Table 1). These processes include learning about condition and health needs, performing health promotion activities, activating resources, lifestyle management and sense-making.

Category	Self-management Processes/Tasks
Focusing on health needs	Learning about condition and health needs
	Taking ownership of health needs
	Performing health promotion activities
Activating resources	Utilize healthcare resources
	Managing social support
	Seeking community resources
	Benefitting from psychological and spiritual resources
Living with a chronic condition	Lifestyle Management
	Sense-making

Table 1. Self-management processes and tasks adapted from Schulman-Green et al. (2012).

2.3. Telehealth Programs for Self-Management

The use of information and communication technologies (ICT) has the potential to enhance self-management and facilitate the principles of the chronic care model (Gee et al., 2015). For instance, digital personal health records could help the patient prepare for upcoming appointments, view their health status, and work collaboratively with the healthcare provider to decide on a suitable treatment (Gee et al., 2015), while mobile technologies could support self-monitoring disease symptoms and medication reactions (Guldmond & Hercheui, 2012). ICT-based

programs can also support health promotion at a global scale facilitating not only therapist-to-family training but also family-to-family coaching. The group context provides an opportunity for parents to coach each other and share their own experiences, mobilizing community resources (Hepburn et al., 2016).

Telehealth is one ICT-based practice that has been used to deliver self-management programs at a distance (Hanlon et al., 2017). These programs include skills training, anxiety therapy, behavior analysis and therapy for the child and parent mainly using video conferencing tools (Ferguson et al., 2019; Hepburn et al., 2016; Kane & DeBar, 2023; Sutherland et al., 2018). There are programs to educate, train and coach parents and teachers of children, either self-directed or therapist-delivered (Ellison et al., 2021; de Nocker & Toolan, 2023; Valentine et al., 2021).

Studies that target toddlers to early teenage years include the parents as the direct recipient of the programs (Ellison et al., 2021). These programs focus on specific problem behaviors in the child, functional communication training or imitation skills training (Kane & DeBar, 2023; de Nocker & Toolan, 2023; Sutherland et al., 2018). However, to support self-management, it is important to consider additional target behaviors in community setting and the acquisition of academic skills, vocational skills and additional daily living skills. In addition, many programs deliver behavioral therapies focused on decreasing challenging behaviors. This deficit-based approach mainly targets the individual's perceived deficiencies, problems, and limitations, rather than their cognitive strengths, diverse way of being, and natural talents (Dinishak, 2022).

There is a scarcity of programs for adolescents and adults teaching transferrable vocational skills and daily living skills for various community-based situations (Domínguez-Lucio et al., 2023; Ferguson et al., 2019). Existing programs targeting adolescents transitioning to adulthood, are often limited to only disseminating specific knowledge, such as the content of an employment interview (Lamash et al., 2023). There is also limited research on programs for occupational therapy delivered via telehealth to improve activities of daily living for children and adolescents. However, these programs operate with limited resources such as those only involving a single therapist (Domínguez-Lucio et al., 2023). The occupational therapies targeting daily living, often fail to evaluate or monitor the transference of results to the natural context (Domínguez-Lucio et al., 2023). Therefore, there is no evidence that the children apply the new skills they learned to practice.

There are limited programs encompassing a holistic view of self-management support activities,

such as those outlined by Schulman-Green et al. (2012), which is a significant gap in the current research. For instance, a review of telehealth-based behavior therapies found that there were no programs teaching daily living skills which is an evidence-based, generalizable and socially valid practice (Ferguson et al., 2019). Another limitation is that many of the self-management programs were academic studies piloted in controlled conditions and requiring further research or were not ready for clinical adoption (Lamash et al., 2023; Valentine et al., 2021)

These limitations highlight the need to study clinical telehealth programs that capture all elements of self-management, facilitating a strength-based approach and providing evidence of their effectiveness. To address these limitations, the current study evaluates a well-established clinically implemented program aimed at holistically supporting the health and social care needs of ASD patients and their families.

3. Methodology

The methodology adopted is a case study approach which yields rich qualitative data, capturing nuances and subtleties of self-management aspects that quantitative methods might overlook (Yin, 2009). The case study helps to investigate how the program specifically supports self-management focusing on a bounded single context. The single case study is an interactive telehealth program, called “Now & Next”. This evidence-based program has been running for over 15 years in several countries including Australia, New Zealand, Canada and Finland. The program is designed by clinical psychologists and is delivered online via Zoom and web pages where content is shared, and participants can also contribute. The parents are led by peer facilitators, who have undergone the program themselves, to work in a group with other parents. Through engaging in different activities, parents learn a variety of skills including how to set long-term goals for their child, how to prioritize, identify strengths, how to increase wellbeing and resilience and learn how to partner with and create better relationships with professionals.

The primary data collection method was semi-structured interviews with New Zealand parents who had completed the program at least 1 year prior. A case-study protocol was developed, and the interviewer followed a set of questions derived from that protocol. The interview questions such as “could you describe your experience with the program?” or “what did you find valuable in the program?”, were flexible to allow opportunity to ask follow-up

questions or seek more elaboration about any self-management tasks or outcomes perceived by the parents. The research team approached the organization responsible for delivering the Now & Next telehealth program, and invitations were sent through the organization seeking potential volunteers. Ethical approval was obtained by the University of Canterbury Human Research Ethics Committee.

Data was collected from 13 parents, 4 males and 9 females, from different backgrounds including Pacific and immigrant families. The interviews were audio recorded and transcribed, with the participants’ consent. Interviews were conducted until saturation was reached in themes and patterns and no new information emerged. Reports and leaflets on the program, other documentary evidence describing the program structure and tools, was used to get an in-depth understanding of the program and help interpret the contextual information from the interviews. Additionally, publicly available reviews and interviews from past participants were utilized to confirm data saturation.

The process of data analysis was inductive and iterative, which involved discovering patterns, themes and categories in the data (Patton 2002). The interview data was reviewed and the participant responses were thematically explored to identify the self-management tasks. Fragments from the interview describing self-management outcomes, activities or elements of the program were coded inductively by two research team members (Miles and Huberman 1994). The codes were based on the content of the fragments and were as descriptive as possible to capture its essence. These fragments were then reviewed by the research team together and codes that were conceptually similar were combined into broader categories. These broader categories were compared and translated into the self-management tasks/processes identified from the literature. The themes are outlined in the following section.

4. Results

The results demonstrate the aspects of self-management delivered by the program and the effectiveness of a peer-led group-setting in achieving the skills targeted by the self-management tasks. The online setting was appreciated by all parents especially those who were restricted by geographic or mobility restrictions. All interviewees indicated that the program improved the healthcare outcomes for themselves, their children and their families. The findings are presented using the self-management conceptualization by Schulman-Green et al. (2012).

4.1. Focusing on health needs

These self-management tasks are necessary for the autistic individuals and their parents to take care of their physical health and concerns specific to the condition (Schulman-Green et al., 2012).

4.1.1. Learning about the condition and health needs. The program provided information about autism spectrum disorder, and the potential challenges for the child and their family. Parents learned about the child's unique care needs, how to identify the child's strengths and weaknesses, and what steps they need to take to obtain the care their child requires.

Parent 1 (M): “[prior to the program] we would keep researching. And every website or every research is giving their own view. And we are making a judgment based on what is being what we read. We stopped doing that. We started to say, okay, this is what we want over for our children. So let's see how far we could go.”

4.1.2. Taking ownership of health needs. The parents set self-care goals for the child, themselves and the family to improve their overall health. They would break down the goals into achievable actions. They gained problem solving skills that helped them strategize how to utilize the limited available resources to improve their child's health and well-being. For instance, one parent who was planning to visit another country with their child, started preparing the child for the long plane ride by taking road trips in the car, simulating possible challenges that might arise during the long trip and possible solutions. The parents who could not access a diagnostic specialist or a therapist, sought advice from the other parents in the program group about alternative resources. They became more confident, became more vocal about their child's and family's needs and believed in their capacity to execute the strategies and behaviors needed to achieve their intended development goal for their child.

Parent 1 (M): “So this course actually gave us the ability to bring the power back within the family to say what we can start now, and let's wait for the service when that comes along. So we know there is a delay for speech language therapies. We know there's an occupational delay. But the question is what we could start doing now to bring and start working with the early intervention with <child> that will help us in reaching our goals”

4.1.3. Performing health promotion activities. Parents reported becoming calmer, less agitated and stressed. Working on a goal for themselves, they learned the importance of respite and looking after

their own well-being as well as their child's. The parents' attitude regarding self-care changed, and they started caring about their own physical, emotional, and mental well-being which was perceived as a value outcome of the program. The parent's relationships with their partners improved, regardless of whether the partner also participated in the program or not. Rather than focusing on and tackling their individual tasks, the two parents of the family worked together as one unit, communicating their needs and helping each other out. The parent involved their child and other siblings in the family discussions, fostering open communications and shared decision-making. The entire family was involved, committed, and contributed towards caring for the child. The parents also encouraged the child's positive and active interactions and participation in the family and community.

For parents, impairments in children are often associated with a “grief” mindset. The Now & Next program aims to challenge the traditional “grief” mindset associated with their child's impairment and replace it with the concept of strength and the promise of growth. The parents felt a sense of control and acceptance of the difficulties when caring for the child. The parents felt more appreciative of the small goal achievements of the child and the family. There were feelings of empowerment and positive changes to their outlook about their situation and their child's condition.

Parent 1 (M): “..what I could see is like he started engaging in interacting because it's more fun going out for children. It's more fun doing activities as a family. It's more fun engaging with (child)'s other sibling sand even meeting other people other than our family. That was really good for (child) in terms of the positive outcomes that (child) got.”

4.2. Activating resources

Autistic individuals and their families make use of various resources to help them manage all facets of their condition, including medical, psychosocial, and financial aspects (Schulman-Green et al., 2012). The specific resources chosen to depend on the needs of the individual. Autistic individuals and their families have reported lower healthcare quality compared to individuals with non-autistic disabilities, due to poor access to healthcare, poor communication and system-level problems (Babalola et al., 2024; Weir et al., 2022). Therefore, it is important for the parents to learn about and avail any resource that could assist them in their child's and family's development.

The program, the peer facilitators and the other parents in the group gave them information regarding

available resources and how to access it. Being able to view these resources via the shared screen was helpful to the other parents as they could adopt similar tools in the management of their child's condition. By engaging in the program, the parents assumed an active role in finding early interventions for the child and to use the available resources to make a positive change to the well-being of their child. These early interventions had a significant and positive impact on the child's ability to learn new skills and overcome challenges.

4.2.1. Healthcare resources. The parents learned to assess the different programs available to autistic individuals and select a program. The parents learned how to set goals for their child's development and put it into practice. The peer facilitators and the other parents shared personal resources, such as daily diaries, they've used before to help them interact positively with the healthcare providers. The communication between the parents and the healthcare providers became more effective because the parents were more aware of their child's needs and strengths and could collaborate with the professionals to formulate development strategies for the child. The parents were able to provide constructive feedback on how those strategies helped their child, what needed to be modified, and which strategies might be useful for the next stage. This in turn helped improve their relationship with the professional care team.

Parent 2 (F): "prior to the appointment I sent [pediatrician] some more pdf copies of everything I thought was relevant. So he had this big file on his desk <about that thick> the different documentation that I sent him, but I just felt so empowered going into that meeting. It wasn't me going for them to tell me something. It was actually about me coming to tell you my problem and what they are going to do to support me. So I [had] completely different mindset to the 2 other appointments where I've gone and completely depended on what they're going to tell me."

4.2.2. Social resources. Accessing social resources is an important self-management task, as the social isolation associated with autism has a great negative influence on the parents' wellbeing (Parker & Killian, 2020). The telehealth program's use of visual aids and interactive features allowed the parents to work together on tasks and to share their goals and strategies with the other parents during the session. This allowed parents and the facilitators to provide more relevant personal feedback and mutual support. Through contributing and seeing other parents' goals, they were able to learn how to set goals, how to break down the high-level goals to achievable smaller goals and how

to set actions. The program provided a platform for collective knowledge, expertise, and capabilities of the parents of the program, leading to broader perspectives and more creative solutions to address their child's needs. The group setting with peer facilitators and other parents with autistic children of their own provided knowledge and expertise of caring for a child with ASD. The collective experiences of their peers were a much-valued resource for all parents in the study.

The parents felt a sense of hope and positivity when they learned that other parents have overcome similar situations. They felt comforted and less isolated knowing that other parents go through similar experiences. They felt safe about sharing their personal experiences and challenges with their child. At the end of the 8 sessions the parents were able to continue the interactions with other parents through social media platforms such as Facebook and WhatsApp. This helped maintain their relationships with the other parents and continue exchanging support and information with them even after the 8-week program had ended. However, the parents felt they needed a more structured gathering to ensure regular contact and specific focus of the interactions.

Parent 3 (F): "And people ask specific questions or share specific things to the group. And so for me, if I share something or ask, I mean, it's because I know there's expertise in that group that I want to tap into. it's because I know, and I trust the people.."

Parent 2 (F): "but having a group of people with autistic children and being able to hear their collective experience and understanding each person, like the people that had gone through a diagnosis stage and been able to empathise with each other and been able to share the frustrations that had gone through and really be heard and felt really safe."

4.2.3. Community resources. Learning about goal setting was valuable because institutions grant resources and funding for the child's development based on the specific goals. The parents learned about financial funding they could access through the program. Once they formulated the immediate and long-term goals for their child, the peer facilitators guided them to identify which funds to access to achieve those goals and other alternative funds and how to apply for them.

Parent 4 (F): "And I said but until we get to that time, because you're you're not old enough yet and not ready, let's talk about, getting a driver's license She was like, Oh, my God! I would love to do that! she wanted to work towards it. She had these modified driving car lessons. the OT assessment before she even got to that....oh! they said that she couldn't get driving

license, driving lessons on her with her funding, because she had the opportunity at school, and I said they did not offer the opportunity at school because they would not be prepared to fund a modified vehicle for her. So you know, I just said, just go back to your funders and explain that. And so it gave me the confidence to say that. So I found ways to just negate all of <daughter>'s barriers and so she started doing the driving lessons, everything."

4.2.4. Psychological and spiritual resources. Parents reported the importance of their spirituality and beliefs and how it aligned with what they expected and learned from the program. For example, for some parents it was important to attend the church as a family and include their child in religious activities such as prayers. They reported that prior to the program they were not able to practice their faith fully and felt increasingly isolated. This isolation was further aggravated in some cases due to cultural stigmas of autism and misinterpreting the child's behavior as being "naughty". The program provided them with tools to gradually adapt their plans and communications so that they could rejoin their church community.

Parent 5 (F): "We used to do online, watch a service, and the simple goal was for [child] to come and sit with all of us when we were watching, and not to the whole service, but be able to watch for maybe 10 min with us, you know, sitting down and listening. So that was the goal. And now we have met the larger goal. We don't go to a traditional, you know, big church. It's like a house church where families know each other and know about [child] that he has a disability. And we, you know, we have a small service, and we share meals together. So that was a family goal that was met."

"And so one of the strengths they look at the spirituality so that really helps, because, you know, I can include that. That is one of my strengths, my spirituality. So that's why I said they looked at it holistically. It doesn't omit any part of it."

4.3. Living with a chronic condition

Whilst learning to manage ASD, parents need to transition from focusing solely on their child's condition or their differences to start learning skills and tasks that would enable them to adapt their daily life. They need to ensure the child develops the skills to transition to adulthood with minimal supervision. For the parents themselves, to improve their emotional and psychological well-being they need to process their emotions and assign meaning to their unique challenges. The ability to access an online recording

of the session impacted these self-management aspects, because the parents were able to continuously reflect on what they learned during the program.

4.3.1. Lifestyle Changes. The parents changed their focus from trying to find specialized solutions for the child, to exploring mainstream opportunities, such as attending a regular pre-school. If the child was at school, the parent prepared a profile of strengths, preferred activities and coping strategies which allowed teachers to understand the best approach to include the child in all activities. Participants reported that the teachers expressed their gratitude for the help and were proactive with feedback and requests for more information. The relationship changed from antagonistic and judgmental to a collaborative partnership.

Through the program, the parents' interactions with the child improved because they were able to interpret the child's behavior better and learned the importance of letting the child work more independently. They started getting the child involved in household chores and responsibilities. The program also helped improve relationships and interactions among the family members. During the program the parents had to work on a goal for their family. This activity led to the family spending time together and taking time for family outings and holidays. The parents were also becoming more engaged with their extended family and friends and started enjoying more activities with their child as a united family.

Parent 1 (M): "Starting O. at the kindergarten was a challenge as everything was new and change is something he resisted as much... he was alone and will play by himself and find it hard to follow instructions. We were amazed by the results and how much progress we have made together as a strong team and our champion. O. now gets involved in activities and follows instructions and most importantly tries to communicate with words."

4.1.2. Sense-making. There are many uncertainties and emotional and psychological challenges for the parents and through the program, the parents started to change their emotional state by using coping skills and building resilience which they learned through the program. They used their past experiences and new learnings to approach the challenges in a structured manner and were optimistic. Further, the parents become more goal oriented and started working towards their own personal goals or career-related goals or doing things they were passionate about. After completing the program, the parents were able to reflect on their learnings and process their emotions in a positive manner. For example, some of the parents

reported that they felt guilty prior to the program and thought that they had somehow caused their child's impairment. With the knowledge and tools provided, they were able to redirect their thoughts from the past to the future. They were able to interpret their child's behavior or external pressures in a more positive manner. For instance, they were able to advocate for their child and were open with their extended family and friends about the challenges they were going through.

Parent 6 (F): "using some of those tools, and Now & Next I got me thinking about it, got me doing more, you know.. When you do more, you just.. you're achieving more. And you're kind of getting what you want out of life. So yeah, it got me more..got me doing more things that I'm passionate about, and finding out more"

Parent 2 (F): "And if somebody was to point you right now and say that you did this to your son, and this is it, it doesn't change anything. But what I can do is that you flip them on its head and say it doesn't matter. Even if you never get to the bottom of it doesn't matter what caused it to go wrong. But what you do have control of is right now and what you can do today if you start to think about what you can do differently today to make a difference for your son. This is where you actually going to be able to make a difference and make an impact for him."

5. Discussion and conclusions

The purpose of the study was to evaluate how a clinical telehealth program delivered to parents of children with ASD supported self-management and long-term outcomes. The findings demonstrate the effectiveness of the telehealth program for the parents, for the children and for the extended families. The respondents considered the results life-changing. The results demonstrate that all self-management activities and processes were supported. As suggested by the chronic care model, the completion of the program and continuously engaging with its community support has led to activated and well-informed parents. All participants reported that they gained a sense of agency to access and influence the services and help.

Access to services has significant implications for child's age at diagnosis and choice of treatment options, (Jashar et al., 2019). The parents have the responsibility to access resources and coordinate care (Hodgetts et al., 2017). However, access to ASD services is a significant issue that further burdens the parents (Karpur et al., 2019). Access to trustworthy information, health care and funding was a major theme for all parents. The online delivery allowed participants to access the program and its resources

without the burden of travel and taking time off work (DePape & Lindsay, 2015). Also, the telehealth option was more readily available as it can enroll participants from different parts of the country. It provided valuable access to collective knowledge and experience from other parents, the facilitators, and alumni and that in turn facilitated communication with service providers (Jashar et al., 2019).

For some participants, the first obstacle was to receive a definitive diagnosis which then qualifies them for specialist help and funding. They found it very difficult to communicate with primary care providers (GPs) to ensure a referral to specialist assessment. This is supported by current literature as primary healthcare providers still have a limited understanding of the spectrum and are often unaware of the resources available for ASD, which makes them reluctant to make referrals or direct the families towards suitable care (Weir et al., 2022). The tools provided by the program allowed the parents to monitor and record behavior and provide a more comprehensive picture to their GP which led to a definitive diagnosis.

Other parents had already accessed some services but were struggling to understand how they can self-manage the condition to achieve positive outcomes. Based on a deficit view, they were receiving information focusing on constraints and reduction of undesirable behavior (Dinishak, 2022). Adopting this view made them feel helpless and isolated as the options for their child and their family were limited. The analysis and planning tools allowed them to identify the child's strengths and how they can participate in mainstream activities. The strengths-based approach also led to better relationships and collaboration with teachers and extended families. Teachers and family members became their child's "champions". This provided the parents with increased support and the children with more opportunities and increased independence. Literature highlights that the parents, families, and direct caregivers have the most significant impact on the lives of autistic individuals (Lord et al., 2018). They are instrumental in understanding the unique needs of those with ASD and implementing strategies to support their development and well-being.

A significant finding of the study from a self-management perspective is the shift in attitudes from grief and confusion to a sense of agency and empowerment. Parents reported that they felt in control of their own situation, and they also involved their children in the decisions. They focused on the wellbeing of the family, improved relationships with friends and family and felt positive about the future.

This telehealth program has several unique features. It is not an education program providing information and then expecting the participants to apply the skills after completion. In each of the sessions during the 8 weeks of the program, the parents learn specific techniques and tools and then report about the results at the next session. The tasks are personalized to the context of each participant, and they have a choice. This application and sharing allow them to see immediate results and to seek help from the group when they encounter difficulties. The psychologists and the facilitators delivering the program all have children with ASD and they have their own experience with applying the tools. This is a very important aspect as all participants felt that they were in a safe place and trusted the rest of the group to share personal experiences and feelings. This community belonging continued after the program completion as participants engage with social media groups and continued to share experiences and seek help from other peers.

There are some limitations of the study. The interviews were conducted with parents who completed the program at least one year prior to ensure that long-term outcomes were achieved from the program. While beneficial, the period of lapse may have led to some parents not being able to recall all the elements of the program that facilitated self-management. The participants who chose to be part of the study may also have strong opinions or experiences that differ from other participants. The study also only elicited the perspectives of the parents; other users such as the peer-facilitators may perceive other benefits or drawbacks of the program in facilitating self-management tasks.

The findings from the study have implications for designers and implementers of self-management programs. The online delivery increased access to the parents who were geographically or resource restricted. The group context of the program provided an opportunity for parents to coach each other and share their own experiences (Hepburn et al., 2016). The peer-led setting promotes family-to-family coaching which could help lessen the additional pressure chronic conditions put on already stretched healthcare systems (Adler-Waxman, 2017). The evidence supports the need for programs not only for individuals with ASD but also targeted towards their carers (DePape & Lindsay, 2015). It also supports the case for telehealth provision of such services. It shows the important role of support for self-management for chronic care and how it interacts with community and healthcare services. However, it also shows that such programs need to be tailored to the specific context and services available.

The results indicated lack of knowledge among professionals such as primary care physicians and teachers. This shows the need for future research focusing on programs to upskill providers to better support self-management of ASD. Finally, there were indications that personal cultural and spiritual beliefs play an important role. Some participants were encountering challenges related to cultural stigma of ASD. Other participants found parts of the program such as the picture cues less useful as they could not relate to them. They suggested that the images can be more culturally appropriate. Future research can focus on design incorporating cultural values.

In conclusion, the results of this study demonstrate the value of holistic telehealth self-management programs. The outcomes affect the children, family members and wider communities.

12. References

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