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Telemedicine in the Kingdom of Saudi Arabia: The feasibility of delivering parent-mediated early intervention targeting social communication in autism.

A thesis submitted to the University of Reading in fulfilment for the degree of Doctor of Philosophy in Clinical Language Sciences

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Declaration

I confirm that this is my own work and the use of all material from other sources has been properly and fully acknowledged.

Wafa Alatar

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Abstract

Background: Evidence on the effectiveness of telemedicine in coaching parents of autistic children on naturalistic developmental early interventions (EI) is limited and conducted in Western countries. In the Saudi context, little is known about EI services and the feasibility of telemedicine in coaching parents.

Aims: 1) Examine the literature on the effectiveness of telemedicine in coaching parents to implement naturalistic developmental EI on child's social communication; 2) Investigate parents' and speech and language therapists' (SLTs) perceptions of EI and describe community-based practice with the aim of enhancing it, and 3) Investigate the feasibility of telemedicine to deliver community-based practice in coaching parents.

Methods: A rapid review evaluated intervention characteristics, outcomes, and research quality in nine studies. Action research employed semi-structured interviews with six parents' and four SLTs' investigated the second aim. A sample of 47 parents completed the survey investigating telemedicine acceptability and intention to use. Finally, eleven parent-child dyads participated in a pre-post feasibility study investigating telemedicine's implementation, usability, and acceptability.

Results: Review findings suggest insufficient evidence for the effectiveness of telemedicine on child's social communication. Action research showed that SLTs' EI practice was one-to-one, therapist-implemented or hybrid, with no consistent parent training. SLTs' reported engaging parents in EI was challenging. Findings showed parents have mixed views about the service. Parents reported raising autistic children was effortful, and parents wanted more support. The surveys revealed high telemedicine acceptability, usability, and intention to use. In the feasibility study, parents showed low-moderate fidelity scores for full achievement and scored moderate-high for partial achievement of strategies. No significant treatment difference was observed in children's social communication.

Conclusions: More high-quality research is required to examine the effectiveness of telemedicine applications on child's social communication in community-based settings to support access and continuity of therapy in EI services.

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List of Abbreviations

ASD	Autism Spectrum Disorder
NDI	Naturalistic Developmental Early Interventions
SLT	Speech Language Therapist
EI	Early Intervention
PMI	Parent-Mediated Intervention
ABA	Applied Behavioural Analysis
KSA	Kingdom of Saudi Arabia
PACT	Paediatric Autism Communication Therapy
HMTW	Hanen More Than Words
ESDM	Early Start Denver Model
P-ESDM	Parent-delivered Early Start Denver Model
NICE	National Institute for Health and Care Excellence, United Kingdom
MDT	Multidisciplinary Team
RCT	Randomised Controlled Trial
JASPER	Joint Attention, Symbolic Play, Engagement, and Regulation
NDBI	Naturalistic Developmental Behavioural Interventions
IJA	Initiated Joint Attention
EIBI	Early Intensive Behavioural Intervention
IQ	Intelligence Quotient
PRT	Pivotal Response Treatment
DTT	Discrete Trial Training
DSM-5	Diagnostic and Statistical Manual of Mental Disorders
CDC	Center for Disease Control and Prevention, United States
CITC	Communications and Information Technology Commission, Kingdom of Saudi Arabia
MOH	Ministry of Health, Kingdom of Saudi Arabia
APA	American Psychological Association
WHO	World Health Organization
PSMMC-AC	Prince Sultan Military Medical City, Autism Centre
ITU	Intention to Use
ITUQ	Intention to Use Questionnaire
PCIM	Parent-Child Interaction Measure
SSD	Single Subject Design
HIPAA	Health Insurance Portability and Accountability Act
TAU	Treatment-as-usual

Chapter 1: Introduction

1.1 Summary

The prevalence of children identified with autism spectrum disorder (ASD)[1] is 1% to 1.8% globally (Elsabbagh et al., 2012). Data from the Center for Disease Control and Prevention (CDC) showed 1 in 54 children is diagnosed with ASD in the United States (CDC, 2020). Parents have reported insufficient autism services across different countries in the world (Alnemary, Aldhalaan, et al., 2017; Corcoran et al., 2015; Daniels et al., 2017). A survey completed by 205 families of autistic children in the Kingdom of Saudi Arabia (KSA) showed that 29% of the families travel outside their cities of residence to another city or country to receive EI services, especially those who live in non-major cities (Alnemary, Aldhalaan, et al., 2017).

The increasing prevalence of ASD has provoked widespread public health concern about the generated gap between available resources and consumer demand (Green, 2019; Wainer & Ingersoll, 2013). To solve the inequity of accessing intervention services, researchers suggest redesigning service delivery systems by actively engaging parents in therapy implementation (Green, 2019; Oono et al., 2013). In addition, the use of telemedicine will help overcome the barriers that time and distance create for medically underserved groups (Burke & Hall, 2015; Knutsen et al., 2016).

The KSA is divided geographically into 13 provinces. According to the Communications and Information Technology Commission (CITC), 97.8% of the Saudi population aged 10-74 years have access to the internet in all provinces (CITC Yearly Report p.97, 2020). The expansion of telemedicine services was initiated by the Ministry of Health

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[1] The term Autism Spectrum Disorder (ASD) was used to refer to formal clinical diagnosis.

(MOH) in a qualitative shift with the Saudi 2030 Vision (MOH, 2018). The MOH has launched an application (Seha) that offer audio and video consultations and was able to cover all the kingdom successfully (MOH, 2018). Therefore, coaching parents of autistic children via telemedicine is potentially an effective service delivery model in autism (Ferguson et al., 2019; Unholz et al., 2020).

In evaluating the feasibility of telemedicine implementation in community-based social communication intervention for autism, this thesis addressed issues of accessibility to intervention for rural and mobile populations and the acceptability of parent-mediated intervention using video feedback in Arabic culture. The studies will investigate key areas of implementation, practicality, usability, acceptability, and effectiveness.

1.2 Autism Spectrum Disorder (ASD)

ASD is a neurodevelopmental disorder characterised by persistent deficits in reciprocal interaction, social communication, and the presence of restricted and repetitive behaviours (American Psychological Association [APA], 2013; World Health Organization [WHO], 2021). According to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), the diagnostic criteria for ASD include persistent deficits in two domains i) social communication and social interaction and ii) restricted, repetitive patterns of behaviour, interests, or activities (APA, 2013).

The deficits in the social communication and interaction domain manifested in deficits in social-emotional reciprocity, nonverbal communication, and developing and maintaining relationships. Deficits in social-emotional reciprocity include but are not limited to difficulty initiating or responding to social interaction, abnormal social approach, and difficulty in having back-and-forth conversation. Impaired nonverbal communication such as abnormalities in eye contact and body gestures, difficulty understanding gestures, and poor coordination of verbal and nonverbal communication are also core features of ASD.

Deficits in the restricted or repetitive behaviours domain include i) stereotyped or repetitive motor movements, use of objects, or speech, ii) ritualised behaviours or inflexible adherence to routines, iii) highly restricted, fixated interests that are abnormal in intensity or focus, and iv) hyper- or hypo-reactivity or unusual interest to sensory input. To meet diagnostic criteria for ASD according to DSM-5, the individual must have persistent deficits in each of three areas of social communication and interaction and at least two of four types of restricted, repetitive behaviours. Moreover, these ASD characteristics must be present in the early developmental period and can be diagnosed by history.

The prevalence of ASD globally is between 1% to 1.8% (Elsabbagh et al., 2012). The prevalence of ASD in boys is 4.3 times higher than in girls (CDC, 2020). Recent evidence showed that the incidence of ASD had increased rapidly over time (Hill et al., 2014). Researchers suggest that the increase in ASD prevalence is likely resulting from changes in diagnostic criteria, awareness, and accessibility to autism services (Hill et al., 2014). However, the possibility that ASD has truly increased over time remains to be adequately tested (Hill et al., 2014).

Researchers suggest that ASD is a multifactorial disorder linked to multiple genetic and environmental factors (Rutter & Thapar, 2014). Strong evidence on genetic involvement was established from studies on twins (Rutter & Thapar, 2014). Researchers investigated the aetiology of autism and reported that the heritability among twins ranges between 64% to 91% and have concluded that ASD is due to strong genetic effects (Tick et al., 2016). Moreover, a growing body of evidence links ASD to environmental factors, e.g., prenatal maternal nutrition, medications, and exposure to chemicals (Lyall et al., 2014). However, these environmental factors are reported to associate with a broader range of neurodevelopmental and psychiatric conditions and are not unique risk factors to ASD (Lyall et al., 2014).

Studies of early brain development in ASD reveal atypical growth and abnormal cortical connectivity (Stigler & McDougle, 2013; Sullivan et al., 2014). Researchers reported an imbalance between distal and local cortical connectivity in autistic children with a decrease in distal/global connectivity and an increase in local connectivity (Sullivan et al., 2014). The reported abnormalities were often noticed in cortical regions involved in social and communication development, e.g., frontotemporal regions (Sullivan et al., 2014). The cortical abnormalities in early brain development are likely leading to atypical development in ASD (Sullivan et al., 2014).

Previous research demonstrates that experience facilitates cortical connectivity across brain regions (Walden & Hurley, 2006). Researchers suggest that lack of social engagement will influence cortical specialisation and connectivity, leading to impaired social communication and language (Sullivan et al., 2014). Since the early experiences of young autistic children occur mainly within social interaction contexts, i.e., child-caregiver interaction, deficits in child's ability to engage in social interaction will limit the instances for learning language and social-communication skills (Sullivan et al., 2014). Moreover, early experiences within social contexts are reported to have an important effect on brain development as well as for developmental trajectories in young autistic children (Sullivan et al., 2014). Thus, early interventions that target core deficits in social and communication will have implications on the experience-dependent aspects of cortical development (Walden & Hurley, 2006).

1.3 Early Interventions for Autistic Children

Researchers reported a crucial need for the development of ASD interventions during the first years of life (Bradshaw et al., 2015; Dawson, 2008; Fuller & Kaiser, 2019; Kornack et al., 2014). Early intervention (EI) is recommended practice for autistic children within national guidelines for autism in many countries in the world (Haute Autorité de Santé, 2012; National Institute for Health and Care Excellence (NICE), 2013; Health Council of the Netherlands, 2009). Evidence for the importance of EI is supported by critical periods of brain development and connectivity (Dawson, 2008; Pierce et al., 2016; Sullivan et al., 2014; Wolff et al., 2012). EI is particularly critical for autistic children because, without intervention, the deficits associated with ASD can negatively affect their learning and developmental progress (Dawson et al., 2012).

EI programs work to lessen the identified features and to facilitate overall adaptive, cognitive, communication, and social functioning (Oono et al., 2013; Reichow et al., 2018). Several approaches of EI have been developed to target the core features and related challenges associated with ASD, such as developmental, behavioural, sensory-based, play-based, and animal-assisted interventions (Sandbank et al., 2020). These EI approaches vary in their underlying theories, intervention targets, instructional procedures, and techniques. Although all core features of autism need to be addressed early in childhood, social communication is of particular concern as deficits in this domain are correlated with long-term functioning and independence.

Moreover, researchers suggested that early deficits in social communication and language skills predicted social functioning and independence in autistic adults (Gillespie-Lynch et al., 2012). Thus, targeting social communication skills in EI programs is critical to improving autistic children's ability to live and function independently (Erickson Tomaino et al., 2014). A recent meta-analysis of 29 studies found more significant improvements in social communication outcomes in participants in intervention groups than in control groups following EI (Fuller and Kaiser, 2019).

EI could have an impact on the quality of life of autistic children by altering developmental trajectories and minimising long-term negative effects (Bottema-Beutel et al., 2014; Bradshaw et al., 2015). Researchers reported a reduction in long-term ASD characteristics for six years after the implementation of EI program (Pickles et al., 2016). Another study reported gains on core autism characteristics, and adaptive behaviours were maintained two years after EI (Estes et al., 2015). Long-term language improvements were also reported in ASD children after receiving EI that targets social communication skills (Kasari et al., 2010). In some cases, children who received EI no longer met the criteria for ASD diagnosis (Barnevik Olsson et al., 2015; Estes et al., 2015). Further, EI services may potentially increase access to mainstream education placements and reduce the need for intensive long-term support services (Kovshoff et al., 2011).

1.3.1 The Behavioural Approach

The most widespread approach of early intervention is the Applied Behavioural Analysis (ABA) (Lovaas, 1987). The ABA principles were developed based on Skinner's operant learning theory (Skinner, 1957). The early intensive behavioural intervention (EIBI) is a well-established treatment approach based on the principles of ABA (Reichow et al., 2018). The ABA-based interventions are designed to improve the developmental and educational outcomes of autistic children and other developmental disorders (Eikeseth et al., 2014). In the ABA approach, the target skills are chosen based on functional areas of child's needs and characterised by the discrete presentation of a stimulus, prompting targeted response, and followed by positive reinforcement e.g., toys, in the presence of the targeted response (Sandbank et al., 2020).

The Discrete Trial Training (DTT) is the most common technique used within the EIBI and ABA-based interventions (Eikeseth et al., 2014; Reichow et al., 2018). The DTT involves teaching the child to attend to specific environmental cues using precise antecedent, teaching, and reinforcement practice (Eikeseth et al., 2014). The DTT uses massed-practice periods of preselected tasks and is controlled by adults in highly structured interaction (Eikeseth et al., 2014). The literature on DTT or didactic behavioural model in EI for autistic children has constantly been growing over the past decades. Many published studies have demonstrated the efficacy of the DTT to improve language skills, IQ, and adaptive behaviours (Peters-Scheffer et al., 2011; Reichow et al., 2018). However, the lack of RCTs raise concerns about the quality of evidence for DTT interventions (Hume et al., 2021).

Despite the reported findings from the efficacy studies, the DTT has been criticised for failing to focus on generalisation and spontaneous initiation of communication (Rogers, 2006). By targeting social communication skills using highly structured adult-directed teaching drills, the purpose of functional communication is lost (Rogers, 2006). In response to this limitation, the naturalistic behavioural model was developed (Ingersoll, 2010). In this model, the intervention is delivered in natural environments and focused on the child's initiations and functional social interactions instead of adult-directed teaching (Blackwell & Stockall, 2021).

Many naturalistic behavioural interventions have been developed, e.g., Incidental teaching, Milieu teaching, and Pivotal Response Treatment (PRT) (Blackwell & Stockall, 2021; Lang et al., 2016). The naturalistic behavioural models are also based on Skinner's operant learning theory (Skinner, 1957). Key differences between the didactic behavioural model (e.g., DTT) and the naturalistic behavioural model (e.g., PRT) were defined by McGee et al. (1983). In the naturalistic behavioural model, the teaching episodes are initiated by the child (following child's lead), using intrinsic reinforcers and occur in natural contexts.

Empirical support for the efficacy of the naturalistic behavioural approach in the EI of autistic children is substantial (Hume et al., 2021). However, researchers suggest that ABA-based interventions, including naturalistic behavioural interventions, show some evidence of effectiveness, but limited number of RCTs remains a concern for this type of interventions (Sandbank et al., 2020). Further, most of the established evidence on the ABA-based interventions delivered in a one-to-one basis with an intensity of 20-40 hours per week by a highly trained autism professional (Reichow et al., 2018).

1.3.2 The Developmental Approach

Another approach followed in EI is the developmental approach (also referred to as the developmental pragmatic approach) (Binns & Cardy, 2019; Ingersoll, 2010). This approach is derived from the social pragmatic model of language acquisition (Bates, 1976), and developmental theory (Piaget, 1936). For example, in typical development, infants can engage in synchronised face-to-face interaction in which they can use vocalisations and movements at three months, respond to joint attention at six months, and begin to initiate joint attention at nine months old (Bottema-Beutel et al., 2014).

In the developmental approach, the intervention goals are derived from child's overall developmental profile and delivered in the context of child's daily routines (Sandbank et al., 2020; Wagner et al., 2014). The developmental interventions focus on improving parent-child and child-child interactions as a pathway to improve social communication and other developmental skills (Sandbank et al., 2020). By doing so, the developmental interventions target child's developmental needs and create a framework for individualised treatment plans (Wagner et al., 2014).

Researchers identified five shared components in the interventions based on the developmental approach. These components are following the sequence of typical development, using principles of developmental science, relationship-based, play-based, and child-centred (Wagner et al., 2014). Moreover, the developmental approach focuses on improving the synchrony and reciprocity of parent-child natural interactions by increasing parental sensitivity and responsivity to child's communication bids for optimum child's learning (Wagner et al., 2014). Parental involvement can help overcome difficulties that autistic children may have in conveying information from one setting to another and can promote consistency between home and intervention settings (Smith & Iadarola, 2015).

Some of the well-known developmental models are the DIR/Floortime (Greenspan & Wieder, 2006), SCERTS (Woods et al., 2012), Hanen's More Than Words (Carter et al., 2011), and PACT (Green et al., 2010). These developmental interventions targets core impairments in joint attention, social communication, and social play (Wagner et al., 2014). Moreover, the inclusion of parents in the developmental approach is an important part of the relationship-based nature of the intervention (Wagner et al., 2014).

EIs that target early preverbal behaviours, e.g., synchronised face-to-face interaction and joint attention, are developmentally important for autistic children as they can enhance future language and social development (Parsons et al., 2017). Previous studies of developmental interventions reported improvements in ASD features (Pajareya & Nopmaneejumruslers, 2011; Pickles et al., 2016), joint engagement (Pajareya & Nopmaneejumruslers, 2011), and language skills (Sigman & Ruskin, 1999). Researchers also reported enhanced parent-child synchronicity and social interaction following developmental intervention (Green et al., 2010). A meta-analysis suggests the efficacy of developmental interventions, particularly for supporting the acquisition of social communication skills, which represents a core challenge for young autistic children (Sandbank et al., 2020).

1.3.3 The Naturalistic Developmental Behavioural Interventions

A new approach called the naturalistic developmental behavioural interventions (NDBI) was described by Schreibman et al. (2015) combined the traditional behavioural approach with the developmental approach. The NDBI use a variety of behavioural principles to target developmentally appropriate skills in natural contexts (Schreibman et al., 2015; Tiede & Walton, 2019). The NDBI are delivered primarily during play, but the interaction within this context is controlled by both the child and the adult (Sandbank et al., 2020). Interventions categorised as NDBI include the Early Start Denver Model (ESDM) and Joint Attention, Symbolic Play, Engagement, and Regulation (JASPER) (Tiede & Walton, 2019).

A recent systematic review suggests the NDBI is the most supported intervention approach by evidence from RCTs (Sandbank et al., 2020). Researchers reported significant improvements in child's cognition and adaptive behaviour and for decreasing the severity of ASD features following NDBI (Dawson et al., 2010). Significant gains in parent-child joint engagement following NDBI has been also reported (Kasari et al., 2015). Two meta-analyses suggest that NDBI may be particularly effective for improving social communication, cognitive development, language, and play skills (Sandbank et al., 2020; Tiede & Walton, 2019).

1.3.4 Moderators and Mediators of EI

Several child, family and intervention characteristics can be expected to influence EI outcomes, e.g., the severity of ASD traits, parental stress, and dose of intervention (Debodinance et al., 2017). Expanding knowledge on intervention mechanisms is important to enhance and innovate clinical practice (Pickles et al., 2015). Understanding the predictors of outcomes in EI is crucial to select the most effective EI program for a particular child (Vivanti et al., 2014).

Researchers suggested that social or joint engagement predicted EI outcomes in autistic children (Shih et al., 2021; Smith et al., 2015). Researchers reported that pre-intervention social engagement levels predicted EIBI outcomes, specifically IQ and adaptive behaviours (Smith et al., 2015). A study that examined the mediating effect of joint engagement on children's initiations of joint attention (IJA) following JASPER intervention concluded that time spent in joint engagement mediates 69% of the effect of JASPER intervention on children's social communication skills (Shih et al., 2021). Researchers reported that joint engagement mediates the effect of JASPER specifically on IJA (Shih et al., 2021). Another study proposed social attention as a potential moderator or mediator of outcomes in EI (Dawson et al., 2012). Researchers suggest that EIs that target social attention help increase the opportunities for learning, thereby promoting experience which facilitates cortical connectivity (Dawson et al., 2012; Walden & Hurley, 2006).

Researchers explored core components of JASPER intervention found that parental behaviour mediated the relationship between the intervention and autism scores (Gulsrud et al., 2016). Moreover, researchers reported that mirrored pacing strategy positively mediated the relationship between the intervention and joint engagement (Gulsrud et al., 2016). Mirrored pacing refers to parent's ability to follow their child's lead and mirror child's actions by imitating the way their child is playing (Prinstein et al., 2019). Researchers concluded that mirrored pacing is an active ingredient of JASPER intervention (Gulsrud et al., 2016). Another study also found that parental behaviour, i.e., synchronous communication acts, strongly mediated child's initiation of communication with the parent (Pickles et al., 2015). Findings from both studies suggest that parental interaction behaviour, i.e., mirrored pacing and synchronous communication, led to gains in child's social communication (Green & Garg, 2018; Shih et al., 2021).

Researchers investigating the predictors of ESDM intervention outcomes reported less severe autism traits at the baseline were associated with significant improvements in language skills and overall development (Eapen et al., 2016). Moreover, better play skills at baseline also moderated improvements in child's overall adaptive behaviour (Eapen et al., 2016). Eapen et al. (2016) concluded that autistic children with more severe traits at baseline might need a higher dose of ESDM or a modified version of the intervention.

A meta-analysis of 34 single-subject studies aimed to investigate the moderators that significantly impacted the outcomes of the EI delivered to autistic toddlers (Debodinance et al., 2017). Researchers found that interventions conducted at home (mostly parent-mediated) works well compared to interventions conducted in other settings. Researchers also reported that the effect of the intervention increases with the duration of the intervention (Debodinance et al., 2017). However, other systematic reviews of RCTs and single-subject designs suggested no treatment effect of dose (Nevill et al., 2018) or inconclusive findings from current literature (Oono et al., 2013; Pacia et al., 2021).

1.4 Evidence for Effectiveness of EI in Community-based Settings

Evidence for the behavioural, developmental, and NDBI approaches was established in efficacy studies, i.e., RCTs (Sandbank et al., 2020). Multiple intervention models established evidence in RCTs, with the majority published since 2010 (French & Kennedy, 2018). Despite encouraging progress, it is unclear to what extent the benefits reported in efficacy trials are maintained in real-world settings (Vivanti et al., 2018). Further, limited studies have investigated predictors of EI outcomes in community-based settings (Eapen et al., 2016; Shih et al., 2021; Smith et al., 2015).

PACT program, originally developed and tested in the United Kingdom (Green et al., 2010; Pickles et al., 2016), was adapted for delivery in rural communities in India and Pakistan (Divan et al., 2015). PACT adaptation involved delivering the intervention by non-specialist workers instead of specialised speech and language therapists in a process called 'task shifting' (Divan et al., 2015). Significant treatment effects were reported in parent synchrony and child initiations within dyadic social interactions (Rahman et al., 2016). Researchers concluded that the adapted version of PACT could be delivered successfully in a context with limited resources, i.e., South Asia (Rahman et al., 2016).

Tupou et al. (2019) aimed to evaluate the effectiveness of EIs from single-subject and group study designs that were implemented under real-world conditions, specifically in inclusive preschool settings. Researchers concluded that in 88% of the included studies (n=16), autistic preschoolers had made gains in at least one primary outcome measure. However, researchers reported that most of the included studies had only minimally acceptable levels of quality and more higher quality research is needed (Tupou et al., 2019). Findings from a previous meta-analysis indicate that there is a large gap between EI outcomes observed in community-based settings compared to those reported in efficacy trials (Nahmias et al., 2019). Previous systematic reviews concluded that evidence on the effectiveness of EI in community settings is limited, and there is a need for more high-quality studies (Nahmias et al., 2019; Tupou et al., 2019).

Previous research highlighted the need to bridge the research-to-practice gap in autism early interventions (Vivanti et al., 2018). Providing intervention of adequate intensity to achieve desirable EI outcomes is challenging for healthcare and education systems (Wetherby et al., 2018). Research has suggested that coaching parents to intentionally embed EI strategies during everyday activities can help achieve the intensity of active engagement needed for autistic children (Wetherby et al., 2018). Researchers argue that integrating parent-mediated approach and technology-supported interventions, e.g., telepractice, will rapidly bridge the research-to-practice gap (Wetherby et al., 2018).

1.5 Service Delivery Models for Early Intervention

1.5.1 Who?

Due to the complexity of ASD, a multidisciplinary approach in EI service delivery has been followed in many countries, including the United States, KSA, and United Kingdom (Saudi Health Council, n.d.; Strunk et al., 2017; NICE, 2013). The multidisciplinary team (MDT) consists of but not only a developmental paediatrician, psychiatrist, occupational therapist, speech-language pathologist, psychologist, special education teacher, and social worker. In the multidisciplinary approach, the MDT work with the autistic child in parallel. Each discipline implements its own intervention plan based on discipline-specific outcomes

(Pecukonis et al., 2008). To function effectively, MDT members share common goals and collaborate to provide better outcomes for the autistic child (Strunk et al., 2017).

An interdisciplinary approach can also be used in EI provided to autistic children. Professionals integrate separate disciplines into a single session. That is, the intervention goals are conducted by one or more team members, together with the autistic child, at one time (Jessup, 2007). Moreover, professionals applying an interdisciplinary approach can conduct some of the intervention goals that are traditionally carried out by other disciplines (Jessup, 2007; Körner, 2010).

1.5.2 Where?

Because autism condition is managed by medical and educational professionals (NICE, 2013), EI in autism can be delivered by medical and educational professionals and paraprofessionals (Brewer, 2018). Therefore, EI can be delivered face-to-face or in-person in a home-based setting, clinic-based setting, educational setting, e.g., nurseries or educational centres, and in a combination of different settings, e.g., home-based and clinic-based (French & Kennedy, 2018). EI services can also be delivered remotely using the telepractice delivery model, i.e., telemedicine (Akemoglu et al., 2019).

Telepractice (also known as 'telehealth' or 'telemedicine') is the remote delivery of health care services and clinical information using telecommunications technology (American Telemedicine Association, 2020). There is increasing evidence that delivering EI to autistic children via telemedicine works well and is feasible (Akemoglu et al., 2019). Telepractice delivery model also helps reduce patient and practitioner costs and increase practitioner coverage relative to traditional in-person service delivery models (Burke et al. 2015; Lindgren et al. 2016).

Delivering EI in natural contexts, i.e., at home and in other caregiving settings, is recommended practice for young autistic children (Rogers & Vismara, 2014). Delivering EI in natural contexts, specifically at home, is reported to lead to more gains compared to other settings (Debodinance et al., 2017). Integrating intervention into the child and his or her family's unique and preferred routines promotes intervention throughout the day and expands opportunities for repetition (Wetherby et al., 2018).

1.5.3 How?

Early intervention can be delivered to the autistic child by a therapist, i.e., therapist-delivered intervention, and can be delivered by a parent or caregiver, i.e., parent-mediated intervention (Oono et al., 2013). To be able to provide an effective EI program, researchers suggested actively engaging parents in therapy implementation (Bottema-Beutel et al., 2014; Rogers & Vismara, 2014). In parent-mediated interventions, the parent is the agent of change, and the child is the direct beneficiary of intervention (Bearss et al., 2015).

Moreover, coaching parents to develop strategies for interaction and management of ASD behaviours is reported to be an obvious route in EI and recommended by a Cochrane review (Oono et al., 2013) and NICE guidelines (NICE, 2013). Parent-mediated interventions stem from the theoretical view that enhancing the early social interactions will promote naturalistic opportunities for generalisation outside the immediate treatment context (Harrop, 2014). However, to what extent parent-mediated EI are beneficial to autistic children is an area of growing research and opens a discussion of what is measured and what is expected to change (Rogers & Vismara, 2014).

1.5.3.1 Parent-mediated Early Interventions (PMI). Although EI programs showed promising outcomes in reducing ASD characteristics and promoting social-communication abilities, generalising social skills has been identified as one of the most challenging aspects in training autistic children (Barry et al., 2003). According to Bottema-Beutel et al. (2014), evidence-based intervention programs that showed promising outcomes for generalising social-communication skills involved parents, were developmentally oriented, and have been delivered in play routines within the context of naturalistic interactions. In addition, parental involvement in the intervention of three years old autistic children predicted better academic achievements at age nine and 18 years (Kim et al., 2018).

Parent training programs and parent coaching methods have been found to lead to better generalisation and maintenance of skills than therapist-implemented interventions (Kashinath et al., 2006; Pickles et al., 2016). Systematic reviews that investigated the effect of caregiver-delivered social communication interventions on skill generalisation and maintenance in ASD suggested that PMI often result in the maintenance and generalisation of improvements in social communication skills (Hong et al., 2018; Pacia et al., 2021). Researchers suggested that following PMI, children may have continued to make small gains over time because they have been provided with multiple opportunities to practice social communication behaviours with their parents, and thus, these repeated opportunities may have accounted for their generalisation of skills (Hong et al., 2018).

However, Pacia et al. (2021) reviewed 38 single-subject and 12 group studies found that 17 studies met adequate quality standards, and only 17 studies were classified as having strong quality. Findings from Hong et al. (2018) were obtained from 34 single-subject studies in which two of them were qualitative, and only seven met adequate quality standards. Researchers concluded that better quality research in the generalisation of skills in autism is needed (Pacia et al., 2021). Further, the need to include measures of generalisation in future family-mediated trials to better understand differential patterns of generalisation related to autism severity or child's cognitive profile was highlighted (Pacia et al., 2021). Previous research reported that a quarter of studies did include generalisation measures (Pacia et al., 2021). Thus, future trials are encouraged to use a more systematic and comprehensive approach to the measurement of generalisation (Carruthers et al., 2020).

Training parents allow the generalisation of child's learned skills by providing continual opportunities for practice in different contexts (Dufek & Schreibman, 2014; Oono et al., 2013). Moreover, when the intervention is implemented by the parent or caregiver, it is expected to have an impact on the dose of intervention delivered than therapists alone (Fuller & Kaiser, 2019). Researchers also suggested that employing the skills of parents will allow the opportunity for consistency of management strategies (Oono et al., 2013; Shaffer & Minshawi, 2014). Furthermore, researchers suggest that PMI can reduce parent frustration by helping parents manage child's challenging behaviours (Dufek & Schreibman, 2014).

Several programs emerged to train parents and caregivers to enhance core skills of social and communication in autistic children, e.g., Hanen More Than Words (HMTW), Paediatric Autism Communication Therapy (PACT), and Parent-delivered Early Start Denver Model (P-ESDM). As described earlier in the developmental approach section, these programs focus on changing parent-child interaction by increasing parent sensitivity and responsiveness to child communication through direct training of parents and using video-feedback methods.

PMI target impairments in shared attention, reciprocal interaction, and social-communication abilities by adapting parent's interaction during playing and other natural activities. Parents are trained to use language that matches child's focus of interest and make complementary comments in play to elicit conversational reciprocity and elaborate on the child's topic of conversation by adding new ideas (Carter et al., 2011; Green et al., 2010; Rogers et al., 2012).

Parent-mediated programs vary greatly in duration from one week to two years (Oono et al., 2013). Evidence-based parent-mediated programs are therapist-guided, and training may be offered in groups (Carter et al., 2011) or one-to-one (Green et al., 2010). Training parents may involve bi-monthly or weekly outpatient or home-based sessions with the therapist (Carter et al., 2011; Green et al., 2010). Other higher intensity parent-mediated program involves multiple sessions per week (Kasari et al., 2014).

1.5.3.1.1 Coaching Parents in PMI. Parent training was defined as providing instruction to parents in the targeted strategy outside of the setting in which the skill will be used, e.g., teaching parents in a clinic conference room (Snodgrass et al., 2017). Unlike parent training, parent coaching is a one-to-one process that includes observing parents when using the targeted strategy during the daily natural interaction with the child and providing feedback on how the strategy was applied (Akemoglu et al., 2019; Snodgrass et al., 2017).

Feedback on parent's application of intervention strategies involves positive and corrective feedback (Ingersoll & Dvortcsak, 2019; Snodgrass et al., 2017). The therapist provides positive feedback when the parent correctly applies a strategy and praises their application (Snodgrass et al., 2017). The corrective feedback is provided in an instance in which the parent misses a strategy or shows incorrect application (Snodgrass et al., 2017). Both positive and corrective feedback must include an explanation of child's responses to parent's behaviour (Ingersoll & Dvortcsak, 2019).

However, the growing body of evidence about the effectiveness of PMI was conducted in Western countries (Oono et al., 2013). Therefore, the recommendations related to the implementation of the PMI, e.g., coaching parents and providing feedback, were mostly developed from trials conducted in the West (Oono et al., 2013). A systematic review aimed to highlight autism research conducted in the Arab countries between 1992 to 2012 found that only 5.3% of a total of 75 studies have addressed intervention outcomes (Hussein & Taha, 2013). Further, findings from Hussein & Taha (2013) showed that none of the studies had investigated outcomes of PMI.

Another systematic review aimed to expand the knowledge about autism research in the Arab countries between 1991 to 2014 revealed growth in autism publications in the region

(Alnemary et al., 2017). However, researchers identified 142 papers that contributed to only 6% of the global output of autism research until 2010 (Alnemary et al., 2017). Similar to Hussein & Taha (2013), the review revealed that only 9.2% of the research had been published about treatments and interventions (Alnemary et al., 2017). Although it is unclear whether the intervention studies utilised PMI, researchers highlighted the need to investigate the outcomes of autism interventions generally in the region (Alnemary et al., 2017).

1.5.3.1.2 **Coaching Parents via Telemedicine.** Coaching parents on targeted skills and strategy implementation via telemedicine can be operated in real-time using a two-way communication system (i.e., audio with or without video). It can also be conducted using previously recorded audio or video materials by giving the parents access to instructional content and allows them to watch it independently at a convenient time (Snodgrass et al., 2017). Hybrid approaches of coaching parents were also developed. For example, the therapist may instruct the parent to use specific skills using audio or video web-based materials and provide feedback on parent's performance in real-time technologies (Akemoglu et al., 2019; Wales et al., 2017).

Multiple systematic reviews reported the potential efficacy of delivering PMI via telemedicine (Akemoglu et al., 2019; Neely et al., 2017; Parsons et al., 2017; Unholz-Bowden et al., 2020). Few systematic reviews focused on coaching parents of autistic children via telemedicine (Neely et al., 2017; Unholz-Bowden et al., 2020). Neely et al. (2017) aimed to synthesise fidelity outcomes for interventionists coached via telepractice. Findings from Neely et al. (2017) revealed that participants were able to achieve fidelity when coached remotely in all studies. However, the study was not limited to coaching parents, i.e., involved coaching parents and professionals on autism assessments and interventions and did not evaluate the quality of included studies. Researchers concluded that the evidence is limited due to the small number of studies and variability in procedures.

Unholz-Bowden et al. (2020) investigated the evidence on coaching caregivers and professionals on ABA-based procedures (assessments and interventions) from 30 single-subject and group studies. Researchers reported positive child's outcomes, particularly a decrease in problem behaviour and/or an increase in skill acquisition following intervention in 14 studies and mixed outcomes in four studies. Researchers also reported improvements in caregivers' performance of ABA-based procedures in 15 studies and mixed outcomes in two studies. Researchers concluded that the current literature provides support for telemedicine as a service delivery model for providing ABA-based services. However, these findings must be treated with caution as Unholz-Bowden et al. (2020) did not report a methodological appraisal of included studies.

Reflection and feedback on parent's performance were reported to be an active component for coaching parents in both systematic reviews (Neely et al., 2017; Unholz-Bowden et al., 2020). According to Unholz-Bowden et al. (2020), 90% of the studies performed live sessions and 87% used performance feedback method. Reflection and feedback on parent's performance can be given immediately in real-time during videoconferencing, i.e., by watching live parent-child interaction or on previously recorded material, e.g., video-feedback strategy (Lerman et al., 2020). Researchers suggest that real-time communication systems support the delivery of services and positively influence the clinical outcomes achieved via telemedicine (Wales et al., 2017).

Findings from previous reviews indicate that real-time videoconferencing is an efficient way of service delivery as it is the closest medium that resembles in-clinic face-to-face interactions but with distance (Akemoglu et al., 2019; Ferguson et al., 2019). Previous systematic reviews revealed that videoconferencing was an efficient medium to provide remote training and feedback to parents of autistic children (Akemoglu et al., 2019; Ferguson et al., 2019; Unholz-Bowden et al., 2020). However, Ferguson et al. (2019) assessed the quality of 28 single-subject and group designs and reported that quality ratings were significantly low for all studies except one single-subject study with adequate quality. Similar to Ferguson et al. (2019), Akemoglu et al. (2019) reported a low rating for methodological quality of all included studies (n=12) except for one single-subject study and one group study.

Previous systematic reviews reported that parents included in the reviews resided in the United States (Akemoglu et al., 2019; Ferguson et al., 2019; Unholz-Bowden et al., 2020), Canada (Unholz-Bowden et al., 2020), and Iceland (Akemoglu et al., 2019). Researchers highlighted the need to investigate the feasibility and efficacy of coaching parents via telemedicine in other countries in which cultural differences might impact service delivery models (Ferguson et al., 2019). Findings from previous systematic reviews showed that limited research had been published about autism interventions in the Arab countries (Alnemary et al., 2017; Hussein & Taha, 2013).

Furthermore, a social justice movement called the neurodiversity movement began among autistic self-advocates. At the individual level, many of the neurodiversity self-advocates have come to see autism as an inherent part of their selfhood, and political identity, rather than a disorder to be treated (Chapman, 2020). However, research suggested that in a non-Western context, e.g., Indonesia, autism is generally represented by non-Autistic people, i.e., parents of autistic individuals (Hersinta, 2020). Public autism societies in a Western context, e.g., the UK, are represented by autistic individuals and define autism as a disability and spectrum condition (National Autistic Society, n.d.). On the other side, autism societies in a non-Western context, e.g., the KSA, are represented by non-autistic individuals and define autism as a spectrum disorder and condition (Charitable Society of Autism Families, n.d.). It is not clear if differences in autism conceptualisations between Western/non-Western contexts have impacted the aims of interventions. However, such differences may have caused tension to researchers engaged in both Western and non-Western contexts.

Although findings from previous reviews revealed that most of the published research was conducted in the KSA (Alnemary et al., 2017; Hussein & Taha, 2013), to our knowledge, there is no or minimal research investigating PMI delivered via telemedicine in the Saudi context. Researchers pointed out the importance of considering cultural diversity in providing and adapting interventions to autistic children (Davenport et al., 2018). Indeed, the consequences of the COVID-19 pandemic lockdowns and social distancing measures on healthcare delivery accentuate the urgent need to address this gap in the literature. Furthermore, the utility of telemedicine is vital not only under pandemic circumstances but also as a service delivery model with the potential to promote equity in accessing early intervention services (Wales et al., 2017).

In sum, the telemedicine model of service delivery will potentially enhance the accessibility to autism services and trained professionals, especially to families living in rural areas where limited access to autism services has been reported (Alnemary et al., 2017; Knutsen et al., 2016). The nature of telepractice requires caregiver involvement in the EI (Snodgrass et al., 2017). Researchers concluded that the combination of telemedicine and parent coaching has a promising future for autistic children (Ferguson et al., 2019; Unholz-Bowden et al., 2020). Further, parent-mediated programs based on the developmental approach are feasible to deliver EI via telepractice because these programs are conducted in natural contexts and promote child's interaction through parent's responsiveness.

The existing evidence on the effectiveness of using telemedicine in coaching parents of autistic children on developmental-based PMI is limited (Akemoglu et al., 2019; Parsons et al., 2017). Previous systematic reviews focused on ABA-based interventions (Ferguson et al., 2019; Neely et al., 2017; Unholz-Bowden et al., 2020). In addition, current evidence on coaching parents remotely have been conducted in Western countries (Akemoglu et al., 2019; Ferguson et al., 2019; Unholz-Bowden et al., 2020). In the Saudi context, little is known about EI services generally and the feasibility of delivering PMI and coaching parents via telemedicine specifically.

The current research will systematically review the existing evidence on the effectiveness of telemedicine in coaching parents of autistic children to implement naturalistic developmental EI (see Chapter 2). Chapter Three aims to describe SLTs' treatment-as-usual in a community-based setting in order to deliver current EI practice using telemedicine (further discussion about EI services in the KSA is provided in Chapter 3 Sections 3.1 and 3.2). In addition, Chapter Four investigates the experiences of parents of autistic children of the current EI services to inform decisions on the EI program delivered via telepractice (for more discussion on parents' perspectives of the EI services provided by SLTs' generally and in the KSA see Chapter 4 Section 4.1). Moreover, the thesis focuses mainly on the feasibility and acceptability of using telemedicine to deliver PMI for autism in the Saudi context (see Chapters 5 and 6). The evidence for telemedicine implementation and usability generally and within the KSA is further discussed in Chapter Six Sections 6.1, 6.1.3, and 6.1.4.

1.6 Thesis Aims

- To review the existing evidence on the effectiveness of telemedicine in coaching parents of autistic children to implement naturalistic developmental early intervention on social communication skills.
- To investigate parents' and SLTs' perspectives of the EI practice in a Saudi context.
- To describe the treatment-as-usual provided in EI service by the SLTs in a Saudi context.
- To investigate parents' intention to use telemedicine in a Saudi context.
- To evaluate the acceptability and usability of telemedicine and video feedback method to deliver parent-mediated intervention in a Saudi context, i.e., cultural considerations.

Chapter 2: Rapid Review

2.1 Background

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterised by deficits in reciprocal social interaction, social communication, and the presence of restricted and repetitive behaviours (APA, 2013). The global prevalence of ASD is 1% to 1.8% (Elsabbagh et al., 2012). The prevalence of ASD has provoked widespread public health concern about the generated gap between available resources and consumer demand (Green, 2019; Wainer & Ingersoll, 2013).

Internationally, a significant imbalance is reported between the services provided to autistic children in rural areas compared to those who live in major cities (Alnemary, Aldhalaan, et al., 2017; Wales et al., 2017). Insufficient services have been reported by parents and service providers in rural areas in the United States, Australia, and Kingdom of Saudi Arabia (KSA) (Alnemary, Aldhalaan, et al., 2017; Dew et al., 2013; Knutsen et al., 2016). Due to limited services, families of autistic children travel to major cities to meet children needs (Alnemary, Aldhalaan, et al., 2017; Dew et al., 2013).

To solve the disparities of accessing intervention services, researchers suggest improving service delivery systems by benefitting from the advances in technology in healthcare, specifically telemedicine, to deliver ASD interventions (Burke & Hall, 2015; Knutsen et al., 2016). The American Telemedicine Association defines telemedicine as the remote delivery and exchange of medical information and healthcare services using electronic communications to improve patient's clinical health status (ATA, 2020).

Several recent systematic reviews concluded that telemedicine has a promising future for supporting autistic children (Akemoglu et al., 2019; Ferguson et al., 2019; Parsons et al., 2017; Unholz-Bowden et al., 2020). One of telemedicine's greatest potentials lies in its ability to overcome the barriers that time and distance create for medically underserved groups. Moreover, using telemedicine has some advantages over in-person services as it increases parents' access to qualified autism practitioners and reduces the need for either the parent or practitioner to travel to appointments (Lerman et al., 2020). Therefore, it provides more convenient care for autistic children by decreasing the rate of missed appointments (Burke & Hall, 2015; Knutsen et al., 2016).

Findings from systematic reviews suggested that telemedicine is a promising service delivery approach for training parents of autistic children in interventions targeting child's language and social communication (Akemoglu et al., 2019; Ferguson et al., 2019; Simacek et al., 2020; Unholz-Bowden et al., 2020). Findings from two systematic reviews concluded that parents could achieve excellent treatment fidelity using a telemedicine model of service delivery (Ferguson et al., 2019; Unholz-Bowden et al., 2020). Therefore, researchers suggest telemedicine is a feasible way to train parents to deliver early interventions to autistic children (Akemoglu et al., 2019; Ferguson et al., 2019; Unholz-Bowden et al., 2020). Furthermore, high parental satisfaction reported following telemedicine model of service delivery (Bearass et al., 2017; Knutsen et al., 2016; Vismara et al., 2018). However, Pickard et al. (2016) highlighted the importance of providing a therapist-assisted approach, in contrast to a self-directed one, to enhance the acceptability of remotely delivered parent-mediated intervention.

2.2 Description of the Intervention

2.2.1 Parent-mediated

Programs of EIs for young autistic children vary in their theoretical bases, implementation (i.e., therapist-implemented vs parent-implemented), intensities, and durations (Oono et al., 2013). In parent-mediated EIs, the parent is trained to implement the intervention (Bearss et al., 2015). The National Institute for Health and Care Excellence in the

United Kingdom NICE (2013) emphasised the importance of parent involvement for an effective early intervention program. Parent-implemented programs have been found to lead to better generalisation and maintenance of skills than therapist-implemented interventions (Aldred et al., 2004; Hong et al., 2018; Pickles et al., 2016). Also, parent-implemented programs are a cost-effective and valid way to boost the amount of intervention a child can receive (Wainer & Ingersoll, 2013).

2.2.2 Naturalistic Developmental

EI programs based on naturalistic developmental interventions (NDI) use principles of developmental science and follow the sequence of typical development (Wagner et al., 2014). Moreover, the NDI programs are relationship-based, play-based, and child-centred (Wagner et al., 2014). The inclusion of parents in the NDI programs is an important part of the relationship-based nature of the intervention (Wagner et al., 2014).

Several NDI programs have been developed that train parents/caregivers to enhance the social communication skills of young autistic children include Hanen More Than Words (HMTW; Carter et al., 2011), Paediatric Autism Communication Therapy (PACT; Green et al., 2010), and Parent-Early Start Denver Model (P-ESDM; Vismara et al., 2018). These NDI programs focus on changing parent-child interaction by enhancing parental sensitivity and responsiveness to child's communication through direct training of parents. In addition, the NDI programs target impairments in joint attention, reciprocal interaction, and social communication by changing parent/caregiver interaction during playing and other natural routines. See Chapter 1 Section 1.3.2 for further details on the approach.

2.2.3 Parent Coaching

In the NDIs, coaching parents is mostly a one-to-one process that includes observing the parent when using the EI strategy during their daily parent-child natural interaction and providing feedback on how it was applied (Akemoglu et al., 2019; Snodgrass et al., 2017).

Giving feedback on the parent's performance while interacting with their autistic child is reported to be an active component of the parent-mediated NDI program (Neely et al., 2017). Two systematic reviews conducted on training caregivers of autistic children reported that providing performance feedback to caregivers was the most common procedure used during remote training (Neely et al., 2017; Unholz-Bowden et al., 2020). Some parent-mediated NDI programs use video-feedback strategy to support parent's learning process of the EI strategies (Carter et al., 2011; Green et al., 2010). See Chapter 1 Section 1.5.3.1.1 for more details about coachng parents in parent-mediated interventions.

2.2.4 Telemedicine-delivered

While parent-mediated intervention is traditionally delivered face-to-face, telemedicine has also been used as a delivery method (Akemoglu et al., 2019). Researchers reported the potential effectiveness of using telemedicine to deliver parent-mediated NDIs (Akemoglu et al., 2019; Parsons et al., 2017). Telemedicine is different from telehealth in that it refers to remote clinical services, while telehealth is a broader scope of remote health care services, including non-clinical services (AAFP, n.d.). Coaching parents via telemedicine can be operated in real-time using a two-way communication system (i.e., audio with or without video), or by providing access to previously recorded instructional audio or video materials, or by mixing these two approaches, i.e., hybrid approach (Snodgrass et al., 2017; Wales et al., 2017). See Chapter 1 Section 1.5.3.1.2 for more details on coaching parents via telemedicine.

2.3 How Might the Intervention Work?

Reflection and feedback on parent's performance can be delivered live during videoconferencing, i.e., by watching live parent-child interaction or on previously recorded material, e.g., video-feedback strategy (Lerman et al., 2020). Previous studies investigated the effectiveness of training parents remotely to implement ASD interventions have used various modes of delivery, including real-time technologies, e.g., videoconferencing, previously prepared materials, e.g., web-based content and instructional videos, or a combination of these methods (Law et al., 2018; Pickard et al. 2016; Vismara et al., 2018).

However, findings from previous reviews indicate that real-time videoconferencing technology is an effective way of service delivery as it is the closest medium that resembles in-clinic face-to-face interactions but with distance (Ferguson et al., 2019; Reynolds et al., 2009; Wales et al., 2017). Researchers reported self-directed interventions to be less effective than real-time coaching interventions (Ingersoll et al., 2016). Real-time communication systems support service delivery and positively impact the clinical outcomes achieved via telemedicine (Ingersoll et al., 2016; Wales et al., 2017).

Studies of NDIs delivered via telemedicine varied in their methodologies. For example, some studies investigated the effectiveness of NDIs delivered through telemedicine sessions only (Hao et al., 2021; Law et al., 2018; Meadan et al., 2016; Vismara et al., 2013, 2018). Other studies used a hybrid approach in training parents, i.e., in-person and remotely delivered sessions (Guðmundsdóttir et al., 2019; McDuffie et al., 2013). Studies have also shown considerable variation in the intensity and duration in training parents to implement NDIs using telemedicine. For example, two studies reported 12 weekly sessions of coaching parents using videoconferencing (McDuffie et al., 2013; Vismara et al., 2018). However, in McDuffie et al. (2013), the duration of the EI program reached four months, unlike the method used by Vismara et al. (2018), which restricted the EI program to 12 weeks.

2.4 What will this Review Add?

There is a body of evidence exploring the use of telemedicine to train parents to implement ABA-based interventions (Heitzman-Powell et al., 2014; Simacek et al., 2017; Subramaniam et al., 2017; Tsami et al., 2019), and EIBI (Blackman et al., 2020; Fisher et al., 2020; Granich et al., 2016). This includes several systematic reviews investigating the effectiveness of telemedicine using intervention approaches that are ABA-based (Ferguson et al., 2019; Meaden & Daczewitz, 2015; Neely et al., 2017; Unholz-Bowden et al., 2020).

To date, two systematic reviews assessed the effectiveness of delivering parent-mediated interventions via telemedicine has included interventions that are not only ABA-based (Akemoglu et al., 2019; Parsons et al., 2017). There are limited systematic reviews on the effectiveness of telemedicine in training parents to implement NDIs specifically, and so drawing conclusions of the available literature is challenging and limits the generalizability of the results. Establishing evidence on the use of NDIs is important as involving parents and following a naturalistic approach is recommended practice by a Cochrane review and in NICE guidelines (NICE, 2013; Oono et al., 2013).

Parsons et al., (2017) focused on investigating the effectiveness of delivering parent-mediated interventions for children with ASD via telemedicine. Of the seven selected studies, significant improvements were reported in parent knowledge in four studies, parent intervention fidelity in six studies, and children's social-communication skills in three out of the seven studies. Researchers noted that interventions targeting parents' knowledge and treatment fidelity showed statistically significant improvements with large effect sizes when reported. However, large to small effect sizes were reported in the child's improvement in the social communication skills when reported within the studies.

Akemoglu et al. (2019) identified 12 studies of parent-implemented language and communication interventions conducted via telepractice. The interventions used in the included studies were naturalistic developmental behavioural interventions NDBI e.g., ESDM and imPACT, and naturalistic behavioural e.g., Reciprocal Imitation Training and DANCE. Child's communication measures were reported in 11 out of 12 studies. However, Akemoglu et al. (2019) reported variation in the communication behaviours measured by the included studies including verbal and non-verbal social-communication skills with some studies measuring imitation behaviour only. Moreover, Akemoglu et al. (2019) reported the inclusion of one study with no parent-coaching component and two studies with an in-person coaching component.

Current evidence of the effectiveness of coaching parents to implement NDI on the social-communication abilities of young autistic children is not widely evaluated and is likely to be affected by multiple factors. The previous systematic reviews included not only NDIs but also ABA-based parent-mediated EIs (Parsons et al., 2017), included studies with no parent-coaching component (Akemoglu et al., 2019; Parsons et al., 2017), and did not focus on the effectiveness of the parent-mediated EIs on the social-communication skills specifically (Akemoglu et al., 2019; Parsons et al., 2017).

As the world experienced the COVID-19 pandemic, it introduced an unprecedented urgency to establish the evidence on delivering NDIs remotely to ensure the continuity of the intervention provided to young autistic children. The purpose of this rapid review is to review the existing evidence on the effectiveness of telemedicine in coaching parents of autistic preschoolers to implement naturalistic developmental early intervention (NDI) to improve social communication skills.

2.5 Review Question

How effective is telemedicine in coaching parents of autistic preschoolers to implement naturalistic developmental early intervention to improve social communication skills?

2.6 Method

2.6.1 Search Procedure

An electronic search was conducted to identify potential studies using the following databases: MEDLINE, Web of Science, PsycINFO, and The Cochrane Library, yielding 101 records. Additional articles were identified using Google Scholar (n=2), bringing the total to

103 records. Following duplicates removal of 45 records, screening of the remaining 58 studies resulted in 9 articles retained for complete review (Figure 2.1). Four keyword categories were used: telemedicine, autism, parent coaching, and social communication. Mesh terms of each keyword were used when available. For example, the search term used for searching MEDLINE database were telehealth, telemedicine, telepractice, remote-health, rural-health, distance-health, digital-health, distance-learning, video-conferenc*, tele-conference*, internet-based, technology, social communication, social behavio$r, social interaction, social emotional, socioemotional, social skills, social language, pragmatic language, pragmatic?, communication, nonverbal communication, verbal behavio$r, language skills, language abilit*, language disorder*, autistic traits, autistic symptoms, autistic behavio$rs, autistic, autism, autism spectrum disorder, ASD, pervasive development disorder, PDD, pervasive development disorder not otherwise specified, PDD-NOS, asperger*, training parents, training caregivers, coaching parents, coaching caregivers, parent-mediated, parent-implemented, and parent-delivered.

The review was conducted following Cochrane Rapid Reviews Methods Group guidelines (Garritty et al., 2021). The search was limited to peer-reviewed journal articles published in English. Search dates from 12/03/2021 to 15/03/2021 and searched publication date restricted to the period from 01/01/2000 to 28/02/2021 since videoconferencing has evolved in early 2000s (Senft, 2016).

2.6.2 Inclusion and Exclusion Criteria

For inclusion in this review, articles were included if they met the following criteria: 1) inclusion of a child with autism spectrum disorder; age ≤ six years old (as diagnosed using DSM 4 or 5 or ICD 10, with clinical diagnosis confirmed for the purpose of research), using an intervention that is 2) telemedicine-delivered with minimal (≤ 25%) in-person sessions, 3) parent-mediated, 4) involves parent coaching component, 5) involves naturalistic and/or developmental component, 6) reported at least one child's social-communication or autism symptom outcome, and 7) employed group study design (e.g., RCT, pilot), or single-subject experimental study design. Furthermore, group studies with only the following control will be included: 1) no treatment or waiting list, 2) treatment-as-usual, e.g., traditional speech and language therapy or specialist autism nursery, kindergarten, or school provision, 3) in-clinic early intervention, and 4) self-directed online early intervention i.e., without direct coaching of the parent.

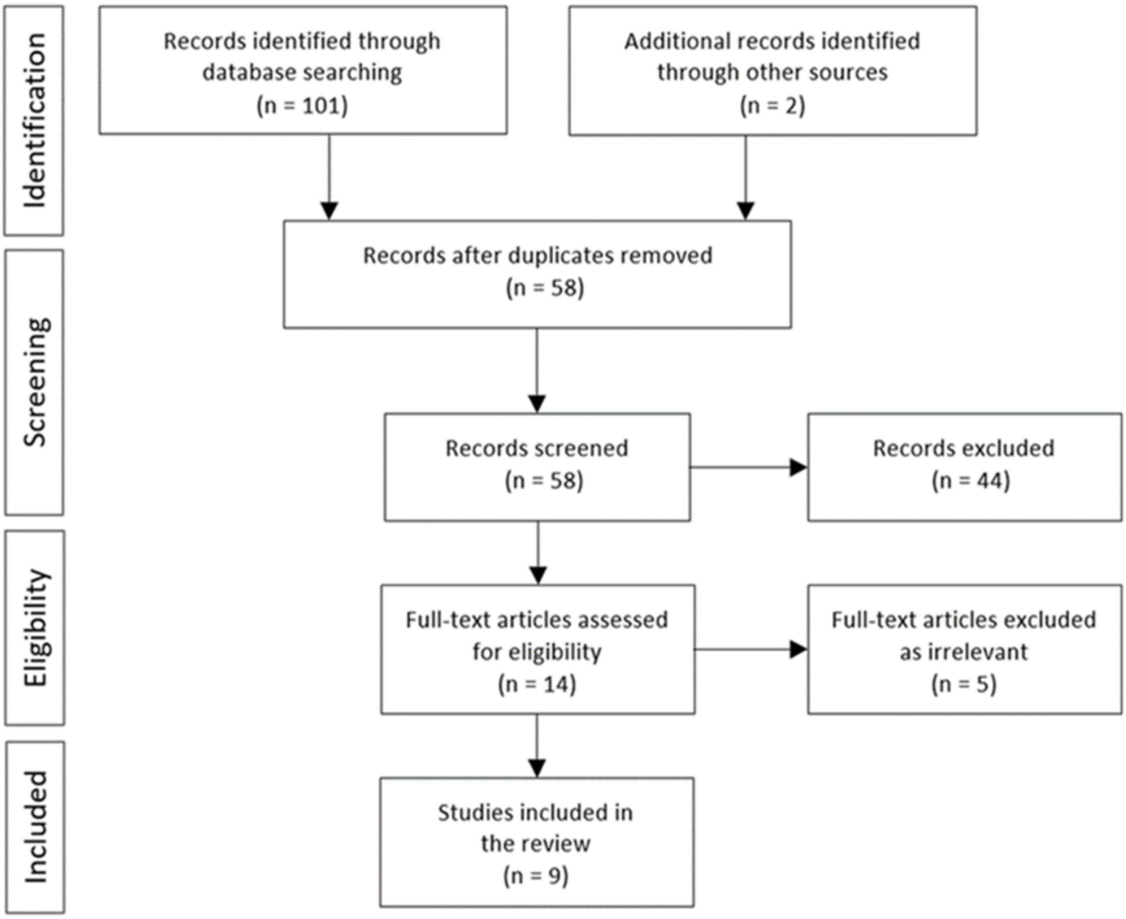

Figure 2.1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Summary of Article Selection Process.

We defined child's social-communication or autism symptom outcome as any form of change in the child's verbal or non-verbal communication behaviour, initiation, and imitation from pre-intervention to post-intervention and follow-up. Change is measured using quantified measures of social-communication and autism behaviours which established psychometric properties. Studies were excluded if 1) autistic preschoolers were age above six years old, 2) used naturalistic developmental EI without parent coaching component, 3) used parent-mediated EI programs that are EIBI or ABA-based, e.g., Discrete Trial Training, Pivotal Response Training, Functional Communication Training, Milieu Teaching, and Incidental Teaching, 4) were systematic or scoping reviews, 5) were group studies with no control group, 6) were non-experimental single-subject designs, and 7) qualitative studies.

2.6.3 Study Selection

One reviewer identified and removed all duplicates and then screened all abstracts and titles against inclusion and exclusion criteria. All irrelevant titles were excluded by one reviewer. All included studies were reviewed independently by a second reviewer. Disputes regarding inclusion were resolved between the first and second reviewers.

2.6.4 Data Extraction

Study characteristics and outcome data were extracted by one reviewer and verified by a second reviewer. To develop an overview of the included studies, the following study characteristics were extracted: participants' characteristics including the number of participants, caregivers' demographics, child's demographics, and geographical location, and intervention characteristics including intervention description, dosage, method of delivery, aims of the intervention or skills targeted, and outcome measures. The review included the data provided in the published papers only. Disputes regarding data extraction were resolved between the first and second reviewers.

2.6.5 Quality of the Studies

The Risk of Bias (ROB-2; Sterne et al., 2019) tool was used to assess the RoB of the randomised controlled trials (RCTs). The RoB-2 tool has five domains to determine the RoB in 1) randomisation process, 2) deviations from intended interventions, 3) missing outcome data, 4) measurement of the outcome, and 5) selection of the reported results. In RoB-2, the study is judged to be at 'low RoB' if all domains were judged to have low RoB. The study is judged to raise 'some concerns' if at least one domain was judged to raise some concerns but not to be at high RoB for any domain. The study is judged to be at 'high RoB' if at least one domain was judged to be at high RoB or the study judged to raise some concerns for multiple domains.

The Single Case Design Risk of Bias (SCD RoB; Reichow et al., 2018) tool was used to assess the RoB of the single-subject studies. The SCD RoB tool evaluates nine domains of bias: two domains to assess selection bias, two domains to assess performance bias, four domains to assess detection bias, and one domain to encompass other sources of bias not included in the other domains. The SCD RoB criteria do not offer an overall RoB judgment. Studies' rigour for the SSD and RCTs was evaluated by two researchers independently. Disagreements in methodological quality were resolved through discussion and consensus.

2.7 Results

A total of nine studies were reviewed and synthesised for five characteristics: 1) study design and participants characteristics, 2) intervention and technology characteristics, 3) parent coaching, 4) child and parent outcomes, and 5) risk of bias.

2.7.1 Design and Participants

Seven of the included studies utilised experimental SSD (Guðmundsdóttir et al., 2017, 2019; Law et al., 2018; McDuffie et al., 2013; Meadan et al., 2016; Vismara et al., 2013; Wainer & Ingersoll, 2015) and two were RCTs (Ingersoll et al., 2016; Vismara et al., 2018). Three studies were conducted in the US (McDuffie et al., 2013; Meadan et al., 2016; Ingersoll et al., 2016), two in Iceland (Guðmundsdóttir et al., 2017, 2019), one in Canada (Wainer & Ingersoll, 2015), one in Singapore (Law et al., 2018), one in the US and Canada (Vismara et al., 2013), and one did not report the country (Vismara et al., 2018).

Across all nine reviewed studies, there were 86 parent-child dyad participants. Only three studies have specified the age and gender of the parents (Guðmundsdóttir et al., 2017, 2019; McDuffie et al., 2013). The child's mean age was 3:4 years, ranging from 1:5-6:1 years. All children received ASD diagnosis except one did not get a formal diagnosis of autism before the study and was diagnosed with PDD-NOS toward the end of the intervention (Guðmundsdóttir et al., 2017). None of the included studies reported details about any co-occurring conditions in their child participants. However, all studies reported participants' education, not all reported ethnicity, and few reported socioeconomic status. Full details of participants age, gender, education, socioeconomic status, ethnicity, and diagnosis are provided in Table 2.1.

2.7.2 Intervention and Technology

The interventions used in the included studies were categorised based on the authors' identification (self-identification) of the intervention category. The majority of the studies (n=5) used NDBI, three used naturalistic behavioural (NB), and one reported the use of naturalistic developmental (ND) intervention. Intervention duration varied across studies from three to 12 months. Three studies used hybrid approach, i.e., combining in-person and tele-sessions, with ≤ 25% in-person sessions (Guðmundsdóttir et al., 2017, 2019; McDuffie et al., 2013). Two studies started with in-person training followed by tele-coaching (Guðmundsdóttir et al., 2019; McDuffie et al., 2013), and one used in-person training sessions at the beginning and throughout the intervention program (Guðmundsdóttir et al., 2017). Further details on the intervention's aims and approach are provided in Table 2.2.

All nine studies reported using a synchronous approach in delivering the intervention (i.e., videoconferencing). Five studies used Skype for videoconferencing (Guðmundsdóttir et

Table 2.1. Study Design and Participants Characteristics.

Study	Design	n	Parent Age and Gender		Child Age and Gender		Parent Education	Socioeconomic Status	Ethnicity	ASD Diagnostic Verification
Guðmundsdóttir et al. (2017)	SSD	2	34, 39	All females	4:10, 5:4	males	1 undergraduate, 1 graduate	-	All Icelandic. No other details.	One received community diagnosis before the study and received PDD-NOS after being recruited.
Guðmundsdóttir et al. (2019)	SSD	3	29-33	All females	3:11- 4.7	males	2 parents had completed vocational training as well as the first 2 years of upper secondary education. 1 undergraduate.	Middle class. No other details.	All Icelandic. No other details.	Community diagnosis of ASD.
Ingersoll et al. (2016)	RCT	27	-	26 females 1 male	1:7-6:1	8 females 19 males	12 with less than a college degree. No other details.	-	6 Minority. No other details.	Met ASD or PDD-NOS in DSM-IV and ADOS-2 or ADOS-G
Law et al. (2018)	SSD	3	-	-	2:5-4:3	1 female 2 males	1 University degree, 2 post-secondary	-	1 Chinese 1 Malay 1 Indian	Met DSM-IV ASD in ADOS-2
McDuffie et al. (2013)	SSD	8	26-38	All females	2:3-5:9	4 females 4 males	years of education: 2 (12years), 2 (14years), 2 (16years), 2 (+16years)	-	-	Community or research diagnosis of ASD.
Meadan et al. (2016)	SSD	3	-	All females	2-4	1 female 2 males	3 college (bachelors/undergrad)	1: 25-45K 1: 65-85K 1: 10-25K	1 Middle eastern 1 Caucasian	Community diagnosis of ASD.
Vismara et al. (2013)	SSD	8	-	7 females 1 male	1:5-3:9	-	4 post college 4 college (bachelors/undergrad)	4: >100K 3: 50-75K 1: 25-49K	1 Latino 6 Caucasian 1 Hispanic	Met DSM-IV criteria and ASD in ADOS.
Vismara et al. (2018)	RCT	24	-	11 females 3 males	1:5-4	3 females 11 males	2 some college, 6 college, 6 graduates	8: less than 75K 6: 75K or more	1 Hispanic 13 non-Hispanic	ASD in ADOS.
Wainer & Ingersoll (2015)	SSD	5	-	-	2:5-4:11	-	1 college (bachelors/undergrad) 4 graduate degree	-	2 Asian 1 Hispanic 1 multi-racial 1 White, non-Hispanic	Community diagnosis of ASD.

SSD Single Subject Design; RCT Randomised Controlled Trial; PDD-NOS Pervasive Developmental Disorder-Not Otherwise Specified; ASD Autism Spectrum Disorder; ADOS Autism Diagnostic Observation Schedule; DSM-IV Diagnostic and Statistical Manual of Mental Disorders, fourth edition.

al., 2017, 2019; Law et al., 2018; McDuffie et al., 2013; Meadan et al., 2016), one study used GoToMeeting (Vismara et al., 2018), one study used a platform developed for the study (Wainer & Ingersoll, 2015), and two studies did not provide details about the platform (Ingersoll et al., 2016; Vismara et al., 2013).

2.7.3 Parent Coaching

All nine included studies utilised live coaching and reflection on parent's performance via videoconferencing, except one study in which coaching was self-directed using Map4Speech application (Law et al., 2018). Three studies used video-feedback strategy to reflect on parent's performance (Law et al., 2018; Meadan et al., 2016; Guðmundsdóttir et al., 2019). In addition, seven studies reported incorporating self-directed intervention material, e.g., website or application (Guðmundsdóttir et al., 2017, 2019; Ingersoll et al., 2016; Law et al., 2018; Vismara et al., 2013, 2018; Wainer & Ingersoll, 2015).

High variation in the amount of tele-coaching provided to the parent was also observed across studies. The minimum tele-coaching time was 270 minutes (Law et al., 2018), and the maximum tele-coaching time was 3180 minutes (Guðmundsdóttir et al., 2017). In some studies, the amount of tele-coaching time varied among participants (Guðmundsdóttir et al., 2017, 2019; Law et al., 2018). The amount of parent's coaching for each study is provided in Table 2.2.

2.7.4 Child and Parent Outcomes

2.7.4.1 Child's Social Communication. Overall, there was little evidence for improvements in child's social communication following the intervention. Four SSD studies reported no significant changes in child's social communication during or following the remotely delivered intervention (McDuffie et al., 2013; Meadan et al., 2016; Vismara et al., 2013; Wainer & Ingersoll, 2015). Child's joint attention was measured in two studies, one SSD and one RCT, with no significant changes observed following the intervention (Vismara et al., 2013, 2018). The outcome of the intervention on child's imitation was reported in two studies. Wainer & Ingersoll (2015) reported no significant change in imitation. However, Vismara et al. (2018) reported observed improvements in imitation for the telemedicine and control (F (1, 64.5) = 4.83, p <.05; P-ESDM M= 1.37, SD= 1.02, Community M= 0.91, SD= 0.78) with no significant difference between groups. Improvements in child's social attending during intervention and follow-up were reported in two SSD studies (Guðmundsdóttir et al., 2017, 2019). However, mean differences between intervention phases were not reported (Guðmundsdóttir et al., 2017, 2019).

Improvements in functional communication were reported in two SSD studies and one RCT (Ingersoll et al., 2016; Law et al., 2018; Vismara et al., 2013). Ingersoll et al. (2016) reported that children in both the therapist-assisted and self-directed groups exhibited significant gains in their communication following the intervention. There were no differences between groups at the end of therapy, yet, the therapist-assisted group made more progress over therapy than the self-directed group, as confirmed by post hoc testing (p= .001 and p= .09 respectively). While visual inspection of the results indicates variability between children in this SSD, Vismara et al. (2013) reported an increase in children's functional verbal utterances from baseline (M= 2.97, SD= 1.83) to follow-up (M= 4.14, SD= 2.04). Visual inspection of Law et al. (2018) SSD results show a more consistent increase in the children's prompted and spontaneous communication confirmed by statistical analysis. Percent non-overlap of all pairs (NAP) for the three children was 76%, 79% and 80% for prompted communication (all significant at a .05 level) and spontaneous communication for two of the children 72% and 82% (both significant at a .05 level).

2.7.4.2 Parent Fidelity. Moderate to high fidelity scores were reported across most studies (n=8). The studies reported 64% (9 out of 15) (Vismara et al., 2018), 66% (2 out of 3) (Guðmundsdóttir et al., 2017, 2019), 75% (6 out of 8) (Vismara et al., 2013), 80% (4 out of

5) (Wainer & Ingersoll, 2015), 94%-100% (3 out of 3) (Meadan et al., 2016), and 100% (3 out of 3) of participants achieved fidelity (Law et al., 2018). One RCT (Ingersoll et al., 2016) reported a significant increase in parent fidelity scores post-intervention (*M*= 3.39, *SD*= .76). However, researchers did not report whether or not all parents achieved fidelity (Ingersoll et al., 2016).

Further, Vismara et al. (2018) reported that five out of 15 parents achieved fidelity post-intervention, and four additional parents achieved fidelity at follow-up. Another SSD study (Vismara et al., 2013) reported overall mean fidelity during intervention was 3.68 (*SD*= .51), with six of eight parents achieved fidelity. Law et al. (2018) reported that all three participants achieved fidelity (*M*= 89%, *SD*= 1.87) ranging from 88%-92% at post-intervention. Mean scores of parent fidelity were not reported in four studies (Guðmundsdóttir et al., 2017, 2019; Vismara et al., 2018; Wainer & Ingersoll, 2015).

Two studies (one RCT and one SSD) reported higher fidelity scores observed when parent coaching was provided (Ingersoll et al., 2016; Meadan et al., 2016). Ingersoll et al. (2016) reported significantly higher fidelity scores for therapist-assisted (involved coaching) than the self-directed (self-guided training) group. Similar findings reported by Meadan et al. (2016) with higher fidelity scores coincided with coaching condition compared to training, baseline, and maintenance conditions.

2.7.4.3 Parent Acceptability and Satisfaction. Seven out of the nine included studies measured parental acceptability and satisfaction post-intervention (Guðmundsdóttir et al., 2019; Law et al., 2018; McDuffie et al., 2013; Meadan et al., 2016; Vismara et al., 2013, 2018; Wainer & Ingersoll, 2015). Two studies used interview method to investigate parental satisfaction following remote intervention (Guðmundsdóttir et al., 2019; Meadan et al., 2016). All seven studies reported high acceptability and satisfaction following remote parent training

Table 2.2. Intervention Characteristics and Outcomes.

Study	Design	Intervention category	Intervention aims	Intervention approach	Dependent variables	Child outcomes	Parent outcomes
Guðmundsdóttir et al. (2017)	SSD	NB	Sunny Starts Teaching DANCE consists of 5 components: (D decide) deciding whether it is a good time to teach, (A arrange) identifying the child's preferences and arranging these events to allow teaching, and (N now) responding to the child's target skill in an immediate and responsive manner. In addition, as part of the Teaching DANCE, the caregiver was taught to (C count and contemplate) monitor progress and pursue interactions that were (E enjoy) effective and enjoyable to both the caregiver and child.	Baseline and training sessions were around 60min twice/week. Duration: 10-12 months. Total coaching: 750-3180min.	2 variables: Parent: teaching episodes. Child: social attending and/or requesting.	When the frequency of teaching episodes changed as training was implemented with each caregiver, the frequency of social attending changed in the same direction (positive). Child behaviours increased during intervention and follow-up observations.	Increase in teaching episodes for 2/3 caregivers. Caregivers' behaviours increased during intervention and follow-up observations.
Guðmundsdóttir et al. (2019)	SSD	NB	Sunny Starts Teaching DANCE; similar to the intervention aims reported in Guðmundsdóttir et al. (2017).	Baseline and training sessions were twice/week. All training sessions lasted between 1.75-2 hr. Duration: 7-12 months. Total coaching: 840-1740min.	4 variables: Parent: teaching episodes; each teaching episode included 3 behaviours: identifying high preference events, environmental arrangement, and responsive event delivery. Child: social attending, requesting, and longer phrases.	Participants' social attending increased during intervention and follow-up observations. No improvements noticed for requesting and longer phrases.	Increase in teaching episodes for 2/3 caregivers.

Ingersoll et al. (2016)	RCT	NDBI	ImPACT Online. No further details about the aims of the program.	12 (75min) self-directed lessons and 24 (30min) coaching sessions twice/week. Duration: no details. Total coaching: 720min.	6 variables: Parent: intervention fidelity, sense of competence, and family impact. Child: language and adaptive skills.	Children in self-directed and therapist-assisted groups improved on language measures, with a trend toward greater gains during a parent–child interaction for the therapist-assisted group.	Parents' intervention fidelity, self-efficacy, and positive perceptions of their child increased. Parents' stress decreased.
Law et al. (2018)	SSD	NDBI	The program adopted from imPACT delivered via Map4Speech iPad App and includes 4 goals: 1. Following child's lead. 2. Imitate & animate. 3. Make moments for togetherness. 4. Prompt, reward, & expand. The goals targeted using 8 stages: (a) introduction, (b) follow your child's lead, (c) imitate and animate, (d) expand your child's language, (e) make moments for togetherness, (f) 2 stages for prompt, reward, & expand, and (g) putting it all together.	8 self-directed lessons (stages) using Map4Speech app at parent's own pace, and 20-29 coaching sessions. Duration: 14-16 weeks. Total coaching: 270-582min.	3 variables: Parent: intervention fidelity measured using 10 parental behaviours, and parental acceptability of Map4speech. Child: child's language (spontaneous and prompted utterances) and pointing gestures (spontaneous and prompted pointing).	2/3 children improved in their functional communication.	Parent's behaviours improved significantly for all participants and maintained high fidelity. Map4speech was highly acceptable by parents.
McDuffie et al. (2013)	SSD	ND	The intervention consists of 4 lessons: (a) follow in commenting, (b) indirect prompting strategies (environmental arrangement, time delay, choice making), (c)	4 (90min) in-person individual lessons provided monthly, each lesson followed by 3 weekly tele-	5 variables: Parent: parent's follow-in commenting, parent's indirect communication prompts, parent's verbal responses to child's	There was an increase in child's total and prompted communication acts from baseline to intervention.	No significant differences between settings were observed for any of the targeted parent's strategies. Parent use of strategies

			taking an active role in child's play, managing play materials, and modelling new play actions, (d) the use of questions to prompt child's communication acts and interactive book reading.	coaching session (total of 16 sessions). Duration: 4 months. Total coaching: no details.	communication acts, and social validity survey. Child: prompted child's communication acts and total child's communication acts.		introduced during in-person parent education and coaching sessions were maintained during tele-sessions.
Meadan et al. (2016)	SSD	NDBI	i-PiCS intervention consists of 4 teaching strategies: (a) modelling, (b) mand-model, (c) time delay, and (d) environmental arrangement.	Training condition: one 45-min parent-training tele-session. Coaching condition: two 30-min coaching sessions/week. Duration: about 3.5 months. Total coaching: around 720min	2 variables: Parent: i-PiCS intervention fidelity (quality and rate of strategy implementation). Child: social communication initiations and responses.	No significant changes in child's social communication skills.	Parents' higher fidelity scores coincided with the coaching condition.
Vismara et al. (2013)	SSD	NDBI	P-ESDM consists of 10 goals: these goals are attention and motivation, sensory social routines, joint activity routines, nonverbal communication, imitation, joint attention, speech development, functional and symbolic play skills, and the teaching techniques and learning contingencies of applied behavioural analysis.	12 weekly (90min) intervention sessions and 3 (90min) monthly follow-up sessions. Duration: 12 weeks. Total coaching: 1080min.	4 variables: Parent: P-ESDM fidelity, parent's satisfaction, and parental engagement. Child: functional verbal utterances and initiated joint attention.	No change on initiated joint attention. Parent reported increased production and comprehension of words and gestures for all children with an average of 100 more words produced and 90 more words understood from baseline to follow-up.	6/8 parents achieved fidelity. All parents were satisfied with remote coaching via videoconferencing. A positive relationship reported between parents' intervention usage and interaction style with children.

Vismara et al. (2018)	RCT	NDBI	P-ESDM; intervention details similar to those reported in Vismara et al. (2013).	90min tele-session/week and access to P-ESDM website vs. treatment as usual and 90min tele-session/month and access to alternative website. Duration: 12 weeks. Total coaching: 1080min.	4 variables: Parent: P-ESDM fidelity, website use, and program satisfaction. Child: joint attention and imitation.	Children's imitation improved for both groups with no significant difference. No improvement reported in child's joint attention.	Higher treatment fidelity reported for P-ESDM group however, not significant. P-ESDM group showed significantly higher satisfaction than control. P-ESDM group showed more use of the website than control.
Wainer & Ingersoll (2015)	SSD	NB	RIT aimed at increasing spontaneous imitation skills using the following strategies: a) environmental modification, b) imitating the child, c) use of simple language, d) use of prompting and reinforcement strategies.	Self-directed condition: self-directed telehealth program consisted of 4 short lessons provided using animated slideshow. Coaching condition: 3 (30min) coaching sessions. Follow-up phase: at one month & three months. Duration: no details. Total coaching: 90min.	5 variables: Parent: intervention fidelity, parent's knowledge of RIT, parental acceptability, and engagement. Child: imitation.	No significant change on spontaneous imitation.	4/5 parents achieved fidelity at some point of the self-directed and coaching conditions. Parent reported higher acceptability to video-based instructions and coaching condition compared to self-directed condition. Parents completed between 12 and 40 components instructional components included on the website (*M* = 33). A strong effect in the change from parents scores on the RIT knowledge quiz after the intervention.

SSD Single Subject Design; RCT Randomised Controlled Trial; NB Naturalistic Behavioural; NDBI Naturalistic Developmental Behavioural Intervention; ND Naturalistic Developmental; P-ESDM Parent-mediated Early Start Denver Model; RIT Reciprocal Imitation Training.

and coaching. In addition, Wainer & Ingersoll (2015) reported higher acceptability for coaching condition compared to self-directed training. However, qualitative findings from only one study revealed difficulties faced by the participants during tele-sessions, including technical problems and difficulty in controlling child's challenging behaviours (Guðmundsdóttir et al., 2019).

2.7.5 Risk of Bias

The evaluation of the methodological rigour of the included studies showed that none of the nine studies met the criteria for low RoB across all achievable domains of the RoB Tools (Table 2.3 and 2.4). Thus, the overall quality of evidence obtained from both the SSD and RCTs is low.

2.7.5.1 Single-Subject Design (SSD). The SCD RoB tool consists of nine quality domains to assess selection bias, performance bias, detection bias, and other sources of bias not included in the other domains (Reichow et al., 2018). Of the seven studies employing a SSD, only two studies were rated for high RoB in one quality domain (McDuffie et al., 2013; Vismara et al., 2013). Three studies were rated for high RoB in two quality domains (Law et al., 2018; Meadan et al., 2016; Wainer & Ingersoll, 2015), and two studies were rated for high RoB in three and five quality domains (Guðmundsdóttir et al., 2017, 2019). The most common risks of bias were failure to blind participants and personnel, selection bias, and failure to use or report the use of blind assessors. However, low RoB was observed in dependent variable reliability, data sampling, and other potential sources of bias for most studies. The detailed rating for each study is provided in Table 2.3.

2.7.5.2 Randomised Controlled Trials (RCTs). The five RoB domains set by Sterne et al. (2019) in the RoB-2 tool was used to evaluate the rigour of the two RCTs included in this review. RoB-2 was used to assess every relevant outcome measure and has three overall

Table 2.3. Rigour Evaluation of SSD Studies Adopted from Reichow et al. (2018).

Study	Selection bias		Performance bias		Detection bias				Other potential sources of bias
	Sequence generation	Participant selection	Blinding of participants and personnel	Procedure fidelity	Blinding of outcomes assessors	Selective outcome reporting	Dependent variable reliability	Data sampling	
McDuffie et al. (2013)	Unclear	Unclear	High	Low	Unclear	Unclear	Low	Low	Low
Vismara et al. (2013)	Unclear	Unclear	High	Low	Low	Low	Low	Low	Low
Wainer & Ingersoll (2015)	Low	Unclear	High	High	Low	Low	Unclear	Low	Low
Meadan et al. (2016)	High	Unclear	High	Low	Low	Low	Low	Low	Low
Law et al. (2018)	High	Low	High	Low	Unclear	Low	Low	Low	Low
Guðmundsdóttir et al. (2019)	High	Unclear	High	High	Unclear	Unclear	Low	Low	Low
Guðmundsdóttir et al. (2017)	High	High	High	High	Unclear	Unclear	Low	High	Low

Table 2.4. Rigour Evaluation of RCT Studies Using RoB-2 (Sterne et al., 2019).

Study	Outcome	Randomisation process	Deviations from intended interventions	Missing outcomes data	Measurement of the outcome	Selection of the reported results	Overall bias
Ingersoll et al. (2016)	Child's language	+	+	+	-	+	-
	VABS communication	+	+	+	-	+	-
	VABS social	+	+	+	-	+	-
	Parent fidelity	+	+	+	!	+	!
Vismara et al. (2018)	Social communication	+	!	+	+	!	!
	Parent fidelity	+	!	+	+	!	!
	Parent satisfaction	+	!	+	+	!	!

+ low risk of bias; - high risk of bias; ! some concerns.

RoB judgments (low RoB, some concerns, high RoB). Overall, the RoB assessment of the two RCTs showed that both studies have a low RoB for the randomisation process and missing outcomes data domains. However, both studies showed some concerns or high RoB for other domains. As shown in Table 2.4, Ingersoll et al. (2016) study was judged to be at high RoB in measuring the outcome domain for the three child's outcome measures and raising some concerns in the same domain for the parent fidelity outcome. The other RCT study (Vismara et al., 2018) met the criteria of some concerns for overall RoB judgement in all evaluated outcomes (one child and two parent outcomes).

2.8 Discussion

There is growing literature on telepractice and parent-mediated autism interventions. This study aimed to improve the understanding of the effectiveness and feasibility of telemedicine in coaching parents of young autistic children to implement specifically NDI programmes. Findings from the synthesis of the nine studies provide preliminary evidence that telemedicine is an effective approach to coaching parents of young autistic children to deliver NDIs. However, the study showed insufficient evidence of the effectiveness of telemedicine in delivering NDIs on child's social communication behaviours, consistent with previous reviews (Akemoglu et al., 2019; Parsons et al., 2017). Participants of three studies showed no improvement in social communication behaviours, although parent fidelity was achieved by all participants (Meadan et al., 2016; Wainer and Ingersoll, 2015; Vismara et al., 2013). A similar discrepancy between parent fidelity and child outcomes was reported following remotely delivered ABA-based interventions (Ferguson et al., 2019).

The variation in the intervention effects on child's behaviours might be due to the disparity in the social communication skills measured in the included studies, consistent with previous reports (Akemoglu et al., 2019). In addition, despite that all included studies reported objective measures of parent-child interaction, it is possible that the used measures were not sensitive enough to detect the changes in child's behaviours. Researchers highlighted the lack of valid objective sensitive measures of change in the social communication skills of young autistic children (McConachie et al., 2015).

It is also possible that the variation in the intervention effects on child's behaviours is due to a time factor. Further, previous research of in-person parent-mediated NDI observed improvement in child's autistic features at follow-up that was not observed post-intervention immediately (Green et al., 2010; Pickles et al., 2016). Research has suggested that the changes in child communication and autism features during treatment could have become self-sustaining after the end of treatment (Pickles et al., 2016). Thus, these findings suggest that the intervention effects on child's communication could occur at some time after the endpoint of the intervention.

Although study findings are inconsistent and inconclusive for child's social communication, they are promising for parental fidelity and acceptability. Overall, the parents in the identified studies were able to learn EI strategies remotely and use them accurately with their autistic children. Most studies reported a significant increase in parent fidelity post-intervention. Higher fidelity scores were observed in the interventions employing parent coaching compared to interventions/conditions with no parent coaching component (Meadan et al., 2016; Ingersoll et al., 2016). This finding is consistent with previous reports of high treatment fidelity achieved by participants who received remotely delivered parent-mediated EIs (Ferguson et al., 2019; Parsons et al., 2017).

Most included studies showed high acceptability and satisfaction amongst parents coached on NDIs via telemedicine, congruent with previous research (Salomone et al., 2017). The study also revealed preliminary evidence of higher acceptability of telemedicine-delivered NDIs incorporating parent coaching than self-directed interventions. Similar findings were reported by Pickard et al. (2016). However, attitudes toward telemedicine may vary regionally and culturally and can possibly be affected by the infrastructure of the location being studied. Thus, the generalizability of the results to other regions in the world must be done with caution.

The study evaluated the methodological rigour of the included studies against RoB quality indicators (Reichow et al., 2018; Sterne et al., 2019). None of the included studies met the criteria for low RoB across all achievable domains of the RoB Tools. All the SSD studies were rated at high RoB in the 'blinding of participants and personnel' domain. However, SSD studies employing parent-mediated interventions might be particularly prone to this type of bias, given that blinding parents to the type of intervention is not possible. Similarly, one of the group studies failed to blind or report blinding of participants and outcome assessors for the selected outcome measures (Ingersoll et al., 2016). The quality assessment results are congruent with previous reports of low-quality research (Ferguson et al., 2019) and lack of blinding in studies utilising telemedicine as an approach to deliver NDI and ABA-based interventions (Parsons et al., 2017).

Furthermore, several limitations were acknowledged in the identified studies. First, there was a high disparity in the amount of tele-coaching provided to the parents between the studies and within some studies (e.g., Guðmundsdóttir et al., 2017, 2019; Law et al., 2018). Although findings from previous systematic reviews investigating the effect of dose in intervention are inconsistent (Debodinance et al., 2017; Nevill et al., 2018; Oono et al., 2013; Pacia et al., 2021), it may affect intervention outcomes. Second, most studies (n=6) did not report the age of the participating parents, i.e., the primary intervention agents. Previous research suggested a correlation between age and the use of video-based telemedicine (Hsiao et al., 2021). Researchers reported that older adults showed lower rates of video-based telemedicine use (Hsiao et al., 2021).

Third, since only two small RCTs were detected and four SSD studies lack numerical data (Guðmundsdóttir et al., 2017, 2019; Vismara et al., 2018; Wainer & Ingersoll, 2015), it is difficult to evaluate and draw a conclusion about effect sizes. Finally, although all studies reported ASD diagnosis, five studies reported community diagnosis of ASD. Thus, it is possible that there have been variations in how the protocols were administered by community practitioners within and among different countries, which raises the possibility for inaccurate diagnosis.

2.8.1 Limitations

Rapid reviews have emerged as an efficient tool for synthesising evidence for health care decision-makers (Garritty et al., 2021). In rapid reviews, the knowledge synthesis methods are streamlined, and processes are accelerated compared to systematic reviews (Garritty et al., 2021). The strength of rapid reviews lies in its ability to provide systematic evidence to inform decision-making and health responses in times of emergency and crisis (Tricco et al., 2017). However, several limitations should be considered when interpreting the results of rapid reviews. First, the search strategy has some limitations, such as the limited number of reviewers, languages included, and publication dates. Second, the review did not include gray literature. Third, a small number (n=9) of studies were included in this review. However, the strengths of the review included searching four databases instead of three databases as recommended by Garritty et al. (2021), strict inclusion/exclusion criteria, and only including peer-reviewed studies. A further strength of this review is that the search terms and strategies were developed with a specialist librarian.

2.8.2 Implications and Future Directions

The COVID-19 pandemic presented an urgent need for healthcare practitioners to support public health precautions and deliver interventions safely by adopting telemedicine services. The evidence for the efficacy of using telemedicine to deliver parent-mediated NDI for autistic children is inconclusive. However, the study has two main implications for researchers and practitioners designing and planning to deliver NDIs via telemedicine. First, the findings from this review indicate that there is a growing number of studies suggesting intervention fidelity can be achieved by coaching parents remotely via videoconferencing. However, since most studies (n=6) have been conducted in North America, the generalizability of the results to other populations is limited. Research has suggested that cultural and social barriers, e.g., religious and social restrictions, influenced the utilisation of telemedicine services in other regions, i.e., the Middle East (AlSamarraie et al., 2020).

Second, the heterogeneity of variables within the social communication outcome in the included studies limited the comparability between studies. This might be due to a lack of valid outcome measures that are sensitive to changes in social communication skills in children below six years (McConachie et al., 2015). Thus, the findings from this study support the need for establishing a robust tool to measure social communication skills in effectiveness trials as an 'urgent research priority' (McConachie et al., 2015). Third, all the included studies were at high RoB in at least one quality indicator of the Cochrane Risk of Bias Tool. Therefore, there is a demand for further high-quality research investigating the effectiveness of telepractice on improving social communication skills that can adhere to a rigorous methodological structure.

Chapter 3: Action Research Study I

3.1 Action Research Overview

The purpose of the action research is to evaluate the early intervention services offered to autistic children in the Saudi context with the aim of developing a consistent approach to intervention planning. In 1992, the first centre for autism in the KSA and the Gulf countries was established in Jeddah by a non-profit organisation (The First Autism Center in Jeddah, n.d.). Jeddah is the second-largest city after Riyadh (the capital) and a port in the western region. Similar initiatives followed the establishment of this centre in the 90s by non-profit and private organisations in the KSA, e.g., Prince Nasser bin Abdulaziz Centre for Autism established in 1998 and was the first centre in Riyadh. These initiatives were followed by governmental support for autism projects to cope with the global increase in autism cases.

A remarkable growth was observed in the services provided to children with developmental disabilities in the KSA. In 2011, the Saudi Health Council established the National Program for Developmental and Behavioural Disorders, which gradually covered 23 cities (Saudi Health Council, n.d.). In addition, the Ministry of Defence Medical Services established Prince Mohammed bin Salman Program for Autism and Developmental Disorders (MBS-PADD) in 2015. MBS-PADD consists of seven centres distributed regionally in the KSA, offering diagnostic and therapeutic services to 1256 autistic children in its first years (Alzahim, 2018).

However, researchers reported the mean age at starting intervention was 3.3 years, suggesting that many children in the KSA did not receive intervention before three years (Alnemary, Aldhalaan, et al., 2017). A survey completed by 205 families of autistic children in the KSA showed that 29% of the families travel outside their cities of residence to another city or country to receive EI services, especially those who live in non-major cities

(Alnemary, Aldhalaan, et al., 2017). Furthermore, 40% of families reported travelling to get autism treatments with or without EI services (Alnemary, Aldhalaan, et al., 2017). According to Alnemary, Aldhalaan, et al. (2017), most autistic children received their intervention in private agencies and at their homes. Although the government approved to cover the cost of private daycare and rehabilitation centres for autistic children in 2014, the study revealed that nearly 80% of the families paid for EI services (Alnemary, Aldhalaan, et al., 2017; Ministry of Human Resources and Social Development, 2017).

One challenge for developing services in the KSA is that only 6% of global autism research has been carried out in the Arab world (Alnemary et al., 2017). Although the largest proportion of autism research in the Arab world comes from the KSA, researchers pointed out that most of the studies published addressed autism biology, risk factors, and diagnosis. According to Alnemary et al. (2017), a small number of papers have addressed autism services, interventions, and life span issues.

To our knowledge, no papers have evaluated the EI practices delivered by the speech language therapists (SLTs) in the KSA. Therefore, describing current EI practices, i.e., services and challenges from the point of view of the SLTs and parents, is necessary to help in i) understanding their needs, ii) selecting or developing EI programs that are culturally appropriate, and iii) improve service delivery models in speech therapy clinics. The two studies described in this chapter and the next aimed to explore the SLTs' EI practices and investigate parents' experiences and expectations related to the EI service provided by the SLTs in this context.

3.2 Introduction

Implementing evidence-based practices, forming collaborative professional-parent relationships and delivering interventions best suited to each child and family requires extensive efforts and expertise (Trembath et al., 2016). Several studies have investigated parent's perceptions of the services provided to their autistic child by ASD providers generally (Alnemary, Aldhalaan, et al., 2017; Salomone et al., 2016; Stahmer et al., 2019; Yi et al., 2020) and by speech language therapists (SLTs) (Auert et al., 2012; Mandak & Light, 2018). However, few studies explored SLTs' practices and perceptions in working with autistic children (Gillon et al., 2017; Mandak & Light, 2018; Trembath et al., 2016), which is the focus of the current study.

Researchers explored the views and experiences of SLTs who work with autistic children and their families in the delivery of assessment and intervention services in community-based settings in different countries (Gillon et al., 2017; Trembath et al., 2016). To better understand SLTs' practices, Gillon et al. (2017) conducted a survey completed by 1114 SLTs working with autistic children and adolescents located in 35 countries, including the KSA. According to Gillon et al. (2017), Hanen, followed by TEACCH and ABA, were the most common programs used by the SLTs. The study also revealed that most SLTs reported providing intervention through individual therapy sessions more than once per week. However, SLTs vary in their involvement in autism interventions, with some respondents reported providing consultations only to child's caregiver or teacher.

Gaining insights into SLTs' involvement with parents/caregivers of autistic children is an important area for investigation (Gillon et al., 2017). According to Gillon et al. (2017), 80% of the SLTs reported always or often working with the parents by enhancing their capabilities to support their autistic child. Findings from parents' interviews emphasised parental needs to be supported and involved by their SLTs in the intervention (Auret et al., 2012).

There has been little work to understand the experiences, involvement, and perceptions of autism professionals, including SLTs, about autism intervention services in the KSA. One study investigated professionals' perceptions about the services provided to autistic children in the KSA (Babatin et al., 2016). The study aimed to assess the perceived availability of services involved 136 professionals recruited from private and governmental autism centres in Jeddah (Babatin et al., 2016). The participants responded to open-ended questions about services' barriers and suggestions to improve these services. According to Babatin et al. (2016), respondents reported that increased professional-to-child ratio and limited family involvement has negatively affected providing adequate service. Respondents suggested increased parental involvement and increased manpower to improve the services provided to autistic children (Babatin et al., 2016). However, the study has some limitations, such as unestablished validity of the questionnaire and risk of bias in questionnaire wording.

As discussed in Chapter 1, describing EI practice in the KSA from both SLTs' and parents' perspectives is crucial for selecting or adapting culturally appropriate EI approaches or programs. The purpose of this study is to describe the EI practices delivered by the SLTs and SLTs' experience in providing EI services in one of the community settings in Riyadh. The study is expected to help to develop a parent-mediated EI based on SLTs' current practice in this community-based setting which will be used in the planned feasibility study. The study is also expected to help build evidence for future KSA intervention research by capturing the current EI practice.

3.3 Study Aims

- To describe and understand SLTs' experience in delivering EI, training caregivers, and related challenges.
- To describe the treatment-as-usual provided in the EI service by the SLTs.
- To develop an intervention plan that covers the goals targeted by the SLTs when working with autistic children.

3.4 Method

3.4.1 Research Context

The study took place in the speech language therapy (SLT) clinic based in the Autism Centre at Prince Sultan Military Medical City (PSMMC-AC) in Riyadh, KSA. PSMMC is one of the largest medical cities and the largest military hospital and the main referral centre for the treatment of armed forces personnel and their dependents in the KSA. PSMMC offers over 30 medical and surgical specialities and specialised centres, e.g., Prince Sultan Cardiac Centre, Oncology Centre, Rehabilitation Centre, and Autism Centre.

PSMMC-AC is one of seven specialised centres established across the Kingdom under MBS-PADD. PSMMC-AC is one of the most specialised ASD centres in the Kingdom, with over 50 employees. It was established in November 2015 with five professions: SLT, Clinical Psychology, Occupational Therapy (OT), Social Services, and Special Education. The SLT team incorporated four licenced speech-language pathologists (SLTs) at the time of data collection. To be a licensed SLT in the KSA, one must get a bachelor's degree in the field from a College of Applied Medical Sciences with a one-year internship.

The Centre provides diagnostic, evaluative, and intervention services to children aged from one to 17 years old. Clinicians from the SLT, OT, and clinical psychology teams work collaboratively with the medical doctors in providing medical services, diagnostic services, and EI services to autistic children. After being diagnosed by the multidisciplinary team, autistic children are referred to clinicians with different specialities, e.g., clinical psychologists, OTs, and SLTs, based on their needs for intervention. The clinicians are expected to implement evidence-based strategies to improve child's sensory, communicative, and behavioural problems through individualised or group therapy sessions. However, it is unclear what EI approaches, intervention targets, and implementation mode, i.e., parent- or therapist-implemented, is used or preferred by the SLTs in this context.

3.4.2 Participatory Action Research Design

To design service-delivery models effectively within a culturally appropriate framework, it is crucial to understand the experiences and needs of the targeted population. SLTs play a central role in the treatment of autistic children. Thus, understanding the experiences of the SLTs in community-based settings is important to enhance EI intervention practices. Since the joint process between researchers and community members is a key component of the participatory action research (PAR), it was selected to investigate the aims of this study (Baum et al., 2006).

PAR in healthcare involves clinical researchers conducting systematic inquiries to improve their own practice, which is expected to enhance patient experience (Koshy et al., 2011). What distinguishes PAR from other research methods is the involvement of the people impacted by the condition being researched (Baum et al., 2006; Koshy et al., 2011; Minkler, 2000). Therefore, PAR offers a research approach consistent with the aims of this study which require involving the people, i.e., SLTs impacted by the condition being research, i.e., EI practices.

Moreover, the PAR approach was chosen to empower the SLTs by engaging them in the process of generating solutions drawing on their intuitions and experiences (Meyer, 2000). Various training and clinical experiences exhibited by the SLTs may affect planning and providing EI to autistic children, i.e., the intensity of the EI program, targeted skills, and strategies used. To be able to describe what approach was followed by the SLTs concisely, PAR was selected. Since action research is situation-based and context-specific (Green & Thorogood, 2018; Koshy et al., 2011), it will help to capture the degree of variation in the intervention applied by the SLTs to autistic children in this context. PAR can be conducted using qualitative, quantitative, or mixed-methods approaches (Koshy et al., 2011). Research has suggested using qualitative methods to capture a rich and in-depth view of participants' experiences (Koshy et al., 2011).

3.4.3 Participating Researchers/SLTs

The study involved four licensed SLTs, three with a bachelor's degree in speech and hearing sciences (SJ, SY, and SR) and one (SG) with a bachelor's degree in speech-language therapy. All participating SLTs were Saudi single females aged 25-27 years old. The SLTs were working at PSMMC-AC at the time of data collection and represented 100% of the SLTs in this setting. SLTs' working experience with autistic children ranged from four-year experiences (SJ), two years and 11 months (SY), 18 months (SR), and four months (SG). Three of the four participating SLTs had minimal exposure to autistic children during their undergrad studies and clinical internship. Only one (SJ) out of the four SLTs had worked with autistic children under supervision during her internship.

3.4.3.1 Recruitment. In an exploratory meeting with the lead researcher in October 2017, three of the SLTs identified the need for more consistent practice and, specifically, the need for developing an EI plan. This meeting was held at the clinic three months before planning the PAR. They also expressed their willingness to work on a project that targets this need. Later, in May 2018, the lead researcher met with all the SLTs who were working at PSMMC-AC to explain and discuss the study and their level of involvement to encourage recruitment. This meeting was held at the PSMMC-AC meeting room for the purpose of this project. The information sheet was handed to the SLTs, and they were asked to take their time to read it and confirm participation. The process of recruiting the SLTs lasted for 20 days.

3.4.3.2 Participatory Process. Since PAR encourages the participants to be involved in all research stages, the SLTs were invited to engage with the whole process, including data analysis, interpretation of findings and planning the action required to improve the current practice. It was acknowledged that the participating SLTs might not have spare time to participate in all the stages of this study. Thus, the SLTs' level of participation was negotiated before each stage and SLTs were informed about their right to discuss and modify any stage when needed. Further, all participating SLTs were involved in recruiting parents and developing a topic guide for parents' interviews used in the following study (see Chapter 4 Section 4.3.4). SLTs' level of participation is shown in Table 3.1.

Table 3.1. SLTs' Level of Participation in the Action Research.

Process	Participating Researcher/SLT			
	SJ	SY	SR	SG
Recruiting parents	√	√	√	√
Developing a topic guide for parents' interviews	√	√	√	√
Coding data from SLTs' interviews	√	√	√	√
Generating themes from SLTs' interviews	√	√		
Defining themes from SLTs' interviews	√	√	√	√
Developing an individual intervention plan	√	√	√	√
Developing a unified intervention plan	√	√	√	√
Collecting data from SLTs' progress reports	√	√	√	√
Planning future actions	√	√	√	√

3.4.4 Data Collection

3.4.4.1 Semi-structured Interviews. One-to-one semi-structured interviews were conducted with the SLTs by the lead researcher. Each SLT was interviewed twice. Interviews are a common tool in qualitative research and have been used by researchers in PAR studies (Kilbride et al., 2011). One-to-one interviews are useful to gather data from people who may not be confident enough to talk in a larger group, e.g., in front of colleagues (Koshy et al., 2011).

3.4.4.1.1 Interview I. The first interview aimed to describe the experience of the SLTs in providing EI to preschoolers with ASD and what factors have shaped their practice. A topic guide of ten open-ended questions was prepared by the lead researcher (Appendix 1). Throughout the interviews, the topic guide was used to elicit SLTs views about the current practice at PSMMC-AC individually. The interview started with some general questions like talk about your experience as SLT and describe your experience at PSMMC-AC. Then, the SLT was asked to describe the EI she provides and her views about the EI service. More specific questions about current EI practice, e.g., what factors affect your decision about the intervention, and what will you do if you wish to change and improve the current practice, were used to provide further understanding. At the end of the interview, the SLT was encouraged to add and discuss any relevant area not addressed by the researcher.

3.4.4.1.2 *Interview II.* The second interview aimed to elicit the commonly used EI intervention goals to describe the SLTs' treatment-as-usual. An EI plan that the SLT team at PSMMC-AC has already developed was used to guide individual discussions between the SLTs and the lead researcher. The EI plan that has been used was initially developed from HANEN It Takes Two to Talk stages of communication (Pepper & Weitzman, 2004) and FIRST YEARS training program (2009), developed by the University of North Carolina at Chapel Hill Division of Speech and Hearing Sciences. The lead researcher asked each SLT to imagine doing an EI plan to an autistic child who is newly diagnosed and had not received any previous intervention services. Each SLT was probed to explain what skills would be targeted, i.e., non-verbal communication, joint attention, playing skills, etc., and to specify the goals used for each skill. They were also asked to refer to the previously developed intervention plan or other resources, if any, i.e., other developed EI programs to compare with the current practice.

3.4.4.1.3 Interview Method. The audio-recorded interviews and discussions were conducted at PSMMC-AC meeting room using Sony ICD-PX370 Mono Digital Voice Recorder. The lead researcher began the interview by explaining the purpose and seeking consent to continue. Participants were encouraged to speak freely when answering and were told there were no correct/incorrect answers. They were also encouraged to add to the topic when there has been something they want to talk about and was not covered in the interview questions. The SLTs' interviews lasted between 36 to 57 minutes.

3.4.4.2 SLTs' Progress Reports. A way to validate findings from qualitative data in health research is by checking if what practitioners do in practice what they say they are doing (Green & Thorogood, 2018). Thus, internal validity was established to the unified intervention plan by collecting notes from patients' medical records, specifically, SLT reports. Every participating SLT was given a form to collect targeted goals from five therapy sessions of different patients to verify what was reported in their individual intervention plans. These goals were checked to ensure consistency between what was said in the interviews and what was reported in SLTs' individual plans. Between 11 to 15 goals were gathered by each participating researcher (a total of 51 goals). The check revealed that all goals were included in the unified plan.

3.4.4.3 Caseload Census. The data reported under this section were collected after the analysis of SLTs and parents' semi-structured interviews in order to determine future action. The SLTs counted the number of patients who had received at least four consecutive therapy sessions, i.e., one session per week for four weeks or more. The period of investigation was from January 2017 to July 2018. This period was chosen because the number of SLTs employed at this duration was solid (three SLTs). Therefore, the number of clients served was expected to resemble a typical flow.

3.4.5 Data Analysis

Data collected from the SLTs were transcribed using Express Scribe Transcription Software and AltoEdge Foot Pedal. SLTs interviews were transcribed for thematic analysis using the approach of Braun and Clarke (2006). Thematic analysis was used since it provides a rich and detailed yet complex interpretation of the data (Braun & Clarke, 2006). It is also reported to be suitable to answer questions related to people concerns about an event or service; why and why not people use service or procedure (Ayres, 2007; Green & Thorogood, 2018).

Inductive thematic analysis was used across the data set to analyse the audio-recorded data collected from the semi-structured interviews. Inductive (bottom-up) analysis is data-driven and is based firmly on what is said by participants (Braun & Clarke, 2006; Creswell, 2014; Green & Thorogood, 2018). Inductive analysis was used initially to ensure a detailed analysis of all data set and not some aspects of the data (Braun & Clarke, 2006).

3.4.5.1 Analysis of Interview I. Broad verbatim transcription of the first interviews of the participating SLTs was conducted by the lead researcher. The transcripts of the SLTs' interviews were checked by a research assistant, an undergrad student, who went through each audio recording to ensure that the whole interview has been transcribed accurately. Disagreements between the transcriber and checker were resolved through discussion and consensus. The interviews were conducted, transcribed, and analysed in Arabic, the primary language for the participants. The quotes then were translated into English for PhD supervision and use in this study. The translation was done by a certified English translator and the researcher.

Data from SLTs' semi-structured interviews were coded line-by-line by the participating SLTs, including their own after all interviews had been conducted and transcribed by the lead researcher. The analysis was done in three participatory meetings. Five days before starting the analysis, a printed handout summarising the thematic analysis method developed from Braun and Clarke (2006) was provided to the participating SLTs (see Appendix 2). The lead researcher was available to discuss and explain the steps of coding and generating themes and encouraged the participating SLTs to ask questions. To familiarise and immerse the participating SLTs with the data, they were provided with a hard copy of the transcripts to read the materials once before the analysis.

The first analysis session lasted for three hours and was attended by three participating SLTs. During this session, the participating SLTs with the lead researcher were divided into pairs. Each pair coded 50% of the data (two interviews) manually. Then, the generated codes from both pairs were added together in shared sheets to reduce the number of duplicated codes. A second analysis session was conducted three days later and lasted for two hours. During this session, each pair of SLTs reviewed the coded interviews of the other pair and edits were made to the codes when needed. At this stage of reviewing the coded data, more concise codes were generated, and some general codes were divided into more specified ones.

The third and last analysis session was held four days later. During this session, the SLTs matched up data extracts with the same codes manually in a similarity-based ordering. After matching together data extracts with the same codes, different codes were sorted into themes, and all the relevant coded data extracts were collated within the identified themes using mind maps. Moreover, themes were generated based on connections between codes within a theme, e.g., the association between ideas and characteristics of services.

Initially, the data were manually analysed into 66 codes based on the similarity of responses and frequency. The codes were sorted into five broad themes. Broad themes were then collapsed into four core themes and 12 sub-themes by eliminating redundancies, discarding seven minor/irrelevant codes, and merging nine closely related codes into six codes. The process of reviewing and refining themes involved examining data at the level of the coded data extracts. An external auditor (senior SLT) who was not involved in the processes of coding and generating themes from SLTs' interviews was asked to read all the collated data extracts for each theme and consider whether they appear to form a coherent

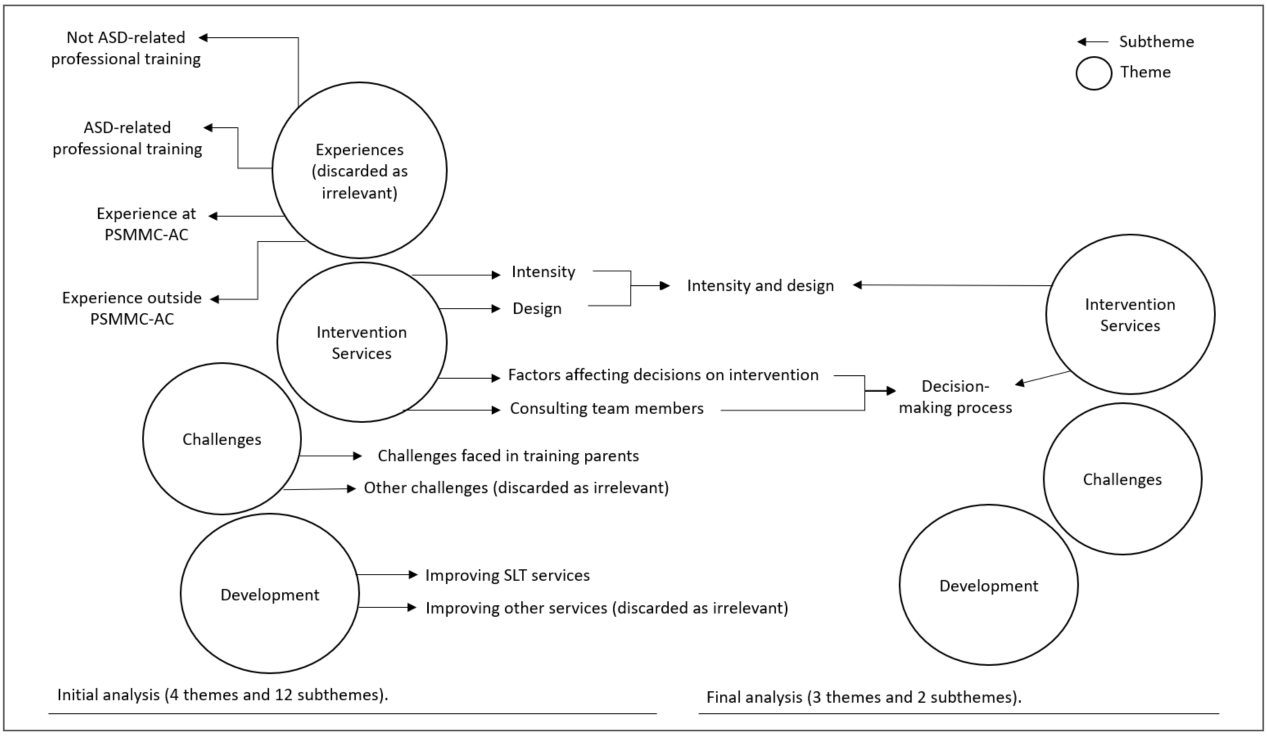

Figure 3.1. Thematic Analysis for SLTs' Interview I.

pattern. Nine data extracts were discarded by the auditor as irrelevant to the codes, and one extract was moved to another code. Finally, to ensure that the themes accurately reflect the meanings evident in the data set as a whole and that there is not too much overlap between them, the themes were defined and named by the participating researchers. The ongoing process of reviewing and refining themes resulted in three broad themes, two sub-themes, and 25 codes (see Figure 3.1 and Appendix 3).

3.4.5.2 Analysis of Interview II. Verbatim transcription of the second interviews of the EI goals was conducted by the lead researcher. Since the process of analysing data underwent ongoing negotiation with the participating SLTs, the participating SLTs and the lead researcher agreed to provide each SLT with her transcribed interview. This step was planned during the analysis stage to give each SLT the opportunity to add further information, i.e., goals that were missed during their interview. The analysis resulted in four individual Tables of EI plans containing the common goals used in the intervention distributed in hierarchy stages, e.g., nonverbal stage, verbal- single words stage ...etc. These goals targeted by different SLTs as provided in their intervention plans were then added together in one unified table by the lead researcher. Following this process, two meetings were arranged to discuss and inform the unified EI plan.

The first meeting lasted two hours with all participating SLTs. During this meeting, the lead researcher presented the unified intervention plan, which included four communication stages with 77 goals to be revised and modified. Through this participatory discussion, the participating SLTs modified the intervention plan to include five communication stages with 86 goals by adding one communication stage and nine intervention goals. The developed unified plan was then presented to the auditor SLT and participating SLTs for final evaluation and refinement in a subsequent meeting which lasted for three hours. During this meeting, the intervention plan was edited by the auditor SLT with the agreement of the participating SLTs. Six goals were added to reach 92 intervention goals distributed in five communication stages.

Analysis of the data gathered from the second interviews involved generating themes that were both inductive/data-driven (i.e., depending on the data) and deductive/theory-driven (i.e., based on researchers' knowledge; themes may emerge from different intervention approaches) (Braun & Clarke, 2006; Green & Thorogood, 2018). Moreover, the data was analysed explicitly, with no interpretation of the data to a level that was beyond what is said or written.

3.4.6 Reflexivity Statement

It is important to mention that the lead researcher is a PhD student situated in the UK and SLT who worked as a member of the speech therapy team in the establishment and development of PSMMC-AC. The participating SLTs were also employed at PSMMC-AC at the time of data collection. All the participating SLTs worked in this context for at least 18 months and were aware of the circumstances that have shaped their practice. The familiarity of the participating researchers with the research problem is crucial to the PAR design. However, the familiarity of the researchers with the research problem and their belonging to the research setting may intentionally or unintentionally shape the interpretations of the findings.

Moreover, the SLTs' interviews were conducted and analysed by the lead researcher who knows and met all the participating SLTs before this study was planned and was a co-worker to one of them. Although the lead researcher had stepped back from working in this context for 20 months prior to conducting the PAR, both the lead researcher and the participating SLTs have shared a similar background. Thus, it is possible that the researchers find it challenging to critically describe the current practice and appraise the SLT service at PSMMC-AC. Furthermore, because the participating SLTs are practitioners who are immersed in work at PSMMC-AC, they may fail to see the obvious about the speech therapy practice in this context.

However, external feedback on the findings was obtained from an external senior SLT who was not immersed in PSMMC-AC services and from Dr Tom Loucas and Dr Fiona Knott, who were supervising this study. Dr Knott is a practicing clinical psychologist who has worked for more than 25 years with autistic children and their families in the NHS and other services. She has experience in qualitative research methodology. Dr Loucas is a practicing speech and language therapist with nearly 30 years of experience working with children with communication disorders, including autism, in the NHS and other services. To minimise bias in analysing data, multiple meetings were held between the researcher and the supervisors to closely review the analysis from the level of codes to the themes' level. These meetings aimed to reflect on the way the experiences of the participating researchers, including the lead researcher, might have affected the way themes were developed.

3.4.7 Ethical Approvals

This study has been reviewed and granted ethical approval by the University of Reading School of Psychology and Clinical Language Sciences Research Ethics Committee (Ethics no. 2018-060-TL) and PSMMC Scientific Research Centre Ethics Committee (Ethics no. 1073).

3.5 Results

3.5.1 Interview I Results

SLTs' first interview aimed to describe and understand SLTs' experience in delivering EI, training caregivers, and related challenges in this context. As shown in Figure 3.1, the data was analysed into three core themes: intervention services, challenges, and development. The themes that fell outside the scope of this study are not included (SLTs' experiences and perspectives that are unrelated to EI and their current practice).

3.5.1.1 Intervention Services. The first theme is related to the EI services provided by the participating SLTs at PSMMC-AC. It emerged from two main subthemes: intensity and design of intervention, and decision-making processes including factors affecting selecting intervention goals and consulting other team members. Moreover, under this theme, the participating SLTs described the current SLT practice at PSMMC-AC.

3.5.1.1.1 *Intensity and Design.* The SLTs described a criterion for the intensity of intervention sessions, which states that autistic children under six years old must be seen regularly (one session per week) and offered EI. However, they reported that the criterion was not always attainable because of their overloaded schedules *'...Any child under the age of 6 is seen on a weekly basis; especially if he is nonverbal… the problem we face now is that we cannot apply this plan for every child – SJ'*. Therefore, to achieve this, some patients were given walk-in appointments during clinic time or office hours.

Although the participating SLTs acknowledged that the criterion wasn't always achievable, subsequent examination of their caseload census revealed that they were only able to provide four consecutive sessions to 7.4% of their patients. Thus, the criterion for the intensity of the intervention sessions was barely achievable. It is not possible to determine what factors led to failure in providing one intervention session every week from this study.

The SLTs discussed the way the intervention session was designed, including parent training, strategies used, and home program follow-up tools. Three SLTs reported taking a brief history about the child's progress and the application of previous goals at the beginning of each session. After taking history and baselining the child on previously targeted goals, the SLTs reported one-to-one intervention offered to the child and the parent. However, parents were not constantly involved and were directly trained by all SLTs. Two SLTs reported providing training and live feedback to parents who are not well educated or show difficulty in applying taught strategies '*...If the parents are educated and are able to understand quickly, I tend to apply it while they observe, but when I feel that they did not get it, I ask them to practice with the child while I observe if their application is correct or not -SY'.*

The use of different intervention approaches was reported by the SLTs. Two SLTs reported a preference to follow a naturalistic approach by training autistic children indirectly through playing, and one reported the use of Discrete Trial Training, an ABA-based technique. The video-feedback strategy was reported to be used in training parents by two SLTs. However, it is unclear from the data whether the differences among the SLTs were related to their previous training, preferences, or child's and family needs.

3.5.1.1.2 Decision-making Process. The data showed several factors affected SLTs' decisions about intervention goals. Some of these factors were child-related, and others were parent-related. Child-related factors such as age, ASD severity, comorbidities, specifically Attention Deficit Hyperactivity Disorder (ADHD), IQ level, language level, and child's enrolment in day-care autism centre were reported by the SLTs. For example, the number of goals targeted at a time will be lessened for a child with a low IQ level or with ADHD. The SLTs also reported some parent-related factors that affected their decisions on designing the intervention. These factors included parent's involvement, parent's preference, parent's educational level, and residency.

Parent's educational level was mentioned by two SLTs to affect decisions on intervention goals e.g., if parents were not well educated or not engaged in the intervention, the number of targeted goals given at a time will perhaps be reduced. Parent's preference was also reported by two SLTs, specifically parent's preference of the intensity of the intervention sessions and what goals they would like to target *'Some parents ask for daily or multiple sessions per week. On the other hand, some families prefer one session per month as they do not have the capabilities to attend weekly – SJ'.*

Parent's location was reported by three SLTs to affect designing child's intervention, specifically, whether parents were able to attend regular therapy sessions or not. In cases where parents were not able to attend regularly, two SLTs reported that the therapy session would be focused on family training. Also, more goals are usually targeted to be achieved over extended periods of follow-ups *'...If the family lives outside Riyadh city, let's say 400 km away from Riyadh, I focus on such cases to educate the parents more than I sit with the child. I also tend to target 3 to 5 goals in each session to be applied in a longer period – SY'.*

Finally, the data showed that each participating SLT turns to other SLTs for consultation with regards to designing intervention plans. This was reported by three SLTs to be evident, especially if they face difficulty with cases that are not commonly seen at PSMMC-AC, e.g., ASD with hearing impairment *'...I often seek the consultation and advice of my colleague speech therapists, especially if the case I'm handling is new to me. For example, I once had a case of a young child (2 years old) with hearing impairment and has* *autism; frankly speaking, I've consulted my colleagues with regard to the plan as I didn't really know from where to start with that child – SY'.*

Further, consulting other team members mainly clinical psychologists and OTs was reported by three SLTs. These consultations were about getting assistance in controlling child's hyperactivity and behaviours, family counselling, and understanding child's sensory profile and did not go beyond that, i.e., did not affect SLTs decisions on intervention. For example, understanding a child's sensory profile has been reported to help the SLT select appropriate reinforcement, e.g., flashing toys or toys with specific colour.

3.5.1.2 Challenges. This theme is about the challenges reported by the participating SLTs. The reported challenges include those related to managing caseload and resources and involving and training parents. The interviews reflected mismatched expectations about parent's role in the intervention as the SLTs reported some challenges faced in engaging parents. The SLTs reported that some parents were not willing to carry out intervention goals and spend time applying the strategies at home. This was expressed by the SLTs to happen because parents did not believe it is their role '*They [the parents] did master the training, but they don't practice it at home because_ maybe because they did not fully believe in their own role – SJ*', or due to other factors, e.g., low education '*When the mother is old and low educated, you see less engagement and home practice, in this case, I feel they rely on us in doing most of this mission...., Some families, of course, they get engaged when you make them feel the importance of their role, however, some families don't - SR*'.

The SLTs reported difficulties convincing parents about their role in improving child's social communication abilities. In such cases, SJ reported spending more time counselling parents and emphasising their role in child's intervention. SY reported making more effort in providing one-to-one intervention sessions when the parent is not engaged *'Some parents are not applying the strategies, so I make more effort trying to cover up their role; I try to add* *more sessions or something like that – SY'*. The SLTs linked this to parents' educational level, their dependence on other assistants, e.g., Nanny or because they do not value their role in intervention.

The SLTs also reported that parents sometimes failed to attend intervention sessions which was reported to affect the flow of the intervention. However, the reasons for not showing or even withdrawing from intervention without notifying the team is not clear from the interviews. In addition, it was reported by one of the SLTs that some parents tend to book more than one intervention session on the same day, which leads the child to lose attention and eventually affects child's training. This is usually exhibited by parents who travel from outside Riyadh' *...In the Autism Centre, there are several specialities: OT, special education, so parents book all the appointments at the same time. So, when the child finally reaches your clinic, he will be already tired and bored. This is actually a problem; when the families book multiple appointments on the same day, the child may interact for 10-min at the beginning of the session, then he gets bored and refuse to interact because he was around from early morning; this usually happens when families are located outside Riyadh, they want to attend all their appointments in the same day; like 4 appointments all in the same day, without caring much about the outcome of the appointment, this surely affects the child – SR'.*

3.5.1.3 Development. The third and final theme is related to SLTs suggestions to develop and enhance speech therapy practices and other services at PSMMC-AC. Recommendations to improve SLT services included developing criteria for the intensity and duration of the intervention program, promoting the generalizability of targeted skills. Two SLTs suggested strict criteria with regards to the number of sessions provided to the child for a certain period and make it more intensive *'I wish for clear criteria; for example, the child must attend a very intensive intervention program – especially young ones – SR'.*

The need for developing criteria for the duration of the intervention program was also suggested by three SLTs. SR reported this matter in 6 different quotes. It was argued that by determining the length of the program for each child, the issue of overloaded schedules would be solved. In addition, children with comparable needs will get equal chances to be served for the same period of time *'Honestly, it's flexible now; the duration is up to the specialist. I believe 6 months maybe adequate. For the purpose of being fair with every case, we don't want to focus on one case at the expense of another. We want to organise the sessions for everyone – SY'.*

The participating SLTs suggested sharing intervention goals with other specialists in the multidisciplinary team to promote the generalisation of skills. Moreover, sharing intervention goals was proposed to offer the child practising opportunities with different people *''It would be very effective if we can involve all the team members in our intervention goals, so instead of being trained in my session only, he will have the chance to take it 5 times, even if it was indirectly at least he gets more training opportunities, specifically the pre-linguistics and language targets can be shared with other teams – SG'.*

The SLTs also suggested active delivery of group therapy sessions and co-sessions and developing written home instructions to guide parents on implementing intervention goals. Co-sessions are sessions provided to the child by two clinicians from different specialities for intervention purposes. Moreover, it is worth noting that the most mentioned suggestion was offering co-sessions which was suggested four times by two SLTs. This may reflect SLTs' need to consult or get support from other team members, e.g., clinical psychologist or OT.

Finally, one SLT emphasised the need to offer parents a meeting with the multidisciplinary team and another individual meeting with a family counsellor before starting the intervention to make sure they understand what is involved and to encourage full participation. During these meetings, the parents will be informed about the condition and the details of the intervention plan. In addition, the level of parent's involvement in the intervention in light of parents' and child's needs will be communicated during these meetings and before starting the intervention.

3.5.2 Interview II Results

Data from SLTs' second interviews that aimed to describe their intervention targets led to the development of an intervention plan by each participating SLT. To capture how the intervention targets differ among SLTs, how individually developed intervention plans vary from the old intervention plan that was used to guide these discussions will be presented. In order to capture the current practice, the SLTs reflected and modified the old intervention plan independently based on their own experience of developing EI plans for autistic children and relating to typical communication development. Each SLT then developed an intervention plan based on the current practice at PSMMC-AC.

First, the old intervention plan has four communication stages and 69 goals targeting child's imitation, playing, and communication skills. The four stages of communication were 1) non-verbal, 2) verbal (single words), 3) verbal (2-3 words/utterance), and 4) advanced. The plan developed by SJ included the same four stages. However, 14 goals were added to reach a total of 83 goals. SY and SR plans also included the same four stages, with 50 and 59 goals, respectively. However, SG asked to modify the first three stages only since her experience was mainly in early intervention, resulting in 26 goals in SG intervention plan.

Moreover, although the number of goals reported by the SLTs varied, the targeted areas were the same, i.e., imitation, playing skills, and communication skills. A unified intervention plan then was developed by all participating SLTs by summing all individual intervention plans and modifying the content. Furthermore, the unified intervention plan contained five communication stages and 86 intervention goals. Finally, in a subsequent

Table 3.2. The Developed Unified Intervention Plan.

Stage	Comprehension	Expression
Stage 1 Non-verbal	Understand routines/ situations. Pretending play. Respond to his name. Attend to sensory social routines. Follow 1-step commands in routine situations. Recognise family members. Identify familiar objects. Identify body parts. Respond to no.	Respond to greetings using social gestures. Request non-verbally by (give me) gesture. Imitate physical actions. Request non-verbally by pointing. Verbal Imitation. Request non-verbally by pointing from distance. Point to show and share. Request verbally (using I want).
Stage 2 Verbal-Single words	Identification of actions. Symbolic play. Follow complex commands. Identify objects/ family members by pointing from distance. Understand "Where" questions. Understand Yes/No questions.	Social imitation. Name familiar objects. Name familiar actions. Refer to self by name. Answer Yes/No questions. Request using 2-words utterance.
Stage 3 Verbal-2-3 words	Understand gender (boy/girl). Follow 2-step related commands. Understand prepositions. Understand adjectives. Imaginative play. Understand quantitative concepts (one, some, all, rest, more). Understand singular/ plural. Understand negation. Understand 1st & 2nd person possessive pronouns (yours, mine, our). Understand 3rd person possessive (his, her, their).	Name gender (boy/girl). Name prepositions. Name adjectives. Use 2-3 word/ utterance. Use "and". Use singular / plural. Refer to self as "me" rather than by name. Use 1st & 2nd person possessive pronouns (yours, mine, our). Use 3rd person possessive (his, her, their). Use 3-word/ utterance consisting of possessive pronouns. Answer "What" & "Where" questions.
Stage 4 4-5 words	Understand the use of objects. Understand subject pronouns (he, she, they). Understand number + noun. Understand comparative adjectives. Understand emotions. Show interest and engage to short stories.	Use 4-5 word/ utterance. Asks "Where" & "What" questions. Describe use of objects using sentence. Use number + noun. Use subject pronoun: (he, she, we, they). Converse simple imaginative tales; describe actions in a book. Answer "Who" & "Why" questions. Answer "Why" & "How" with explanation. Use quantitative concepts (one, some, all, rest, more). Use negation.
Stage 5 Advanced	Understand before & after. Understand time sequences (what happened first, second, last). Understand verb tenses. Understand cause & effect sentences. Answer questions about hypothetical events. Understand advanced cognitive-linguistic skills e.g., false beliefs, theory of mind. Understand advanced morphological markers.	Express emotions. Use analogies, comparisons; can complete opposite analogies ("sister is a girl; brother is a ___). Ask "Why", "How", "Whose", & "When" questions. Ask Yes/No questions. Converse with longer sentences with correct syntax. Use cause & effect sentences. Use before & after. Use comparative adjectives. Use verb tenses. Telling and re-telling stories. Use compound and complex sentences. Understand advanced morphological markers.

participatory meeting involving all participating SLTs, the final version of the unified intervention plan was developed and included 92 goals (Table 3.2).

3.6 Discussion

This PAR aimed to describe SLTs' experience in delivering EI, training caregivers, and related challenges. It also aimed to describe the treatment-as-usual provided by the SLTs in this context to be able to deliver it using new models of service delivery. The study design played a crucial role in investigating the objectives with the active engagement of the people being researched. In participatory health research, the degree to which the targeted population are engaged in the different roles as well the willingness of people to be involved in the research is different (Baum et al., 2006). In this study, all the SLTs working in PSMMC-AC at the time of data collection participated in the research.

The findings from this study showed that the intervention provided by the SLTs to autistic children was therapist-implemented or hybrid approach (delivered by the therapist and the caregiver) and provided on a one-to-one basis. Direct parent training and live feedback were not provided consistently by all SLTs. The interviews showed that the SLTs tend to choose parent-mediated intervention in cases where parents were not able to attend regularly. The traditional one-to-one, therapist-implemented service delivery model has been reported to be helpful in teaching new skills and providing concentrated practice and feedback (Timler, 2008). On the other hand, parent-mediated interventions allow the continual creation of communication opportunities and promote the generalisation of child's skills across different people and situations (Oono et al., 2013). It is difficult to draw a clear conclusion of why the SLTs in this context generally tend to offer therapist-implemented over parent-mediated intervention. However, this might be a consequence of the challenges reported by the SLTs in engaging parents in the EI.

The study intended to elicit SLTs' perception of their current intervention practice. It was reported that the intensity of the EI sessions varied among patients. This variation is due to several factors such as overloaded schedules, parent's preference, and involvement. Although the participating SLTs were aware that the aimed intensity for the EI was not achievable, their perception about how frequent the EI sessions were provided to the autistic children in this context was higher than their actual practice. This might be because they were compensating to provide close appointments to the patients in their free time.

The findings revealed that the collaboration and consultation between team members were strong within the speech therapy team and minimal with other teams. This finding is not surprising, a review of 47 papers aimed to determine the use of interprofessional collaboration within multidisciplinary teams when dealing with autistic children concluded that limited disciplines use the multidisciplinary approach effectively (Strunk et al., 2017). The research has suggested that this could be due to a lack of training in the multidisciplinary approach, organisational constraints, and fear of opposition (Strunk et al., 2017).

The data also highlighted the clinical challenges faced by the participating SLTs during the delivery of the EI. Mainly, challenges related to parental involvement and commitment to the intervention plan were expressed by the SLTs. It is evident that in some cases, the parents did not carry out the home training and spend quality time with their autistic child as the SLT expected. In such cases, the SLTs compensated by increasing the intensity of the one-to-one intervention sessions and provide counselling sessions. It is very important to acknowledge that raising an autistic child is recognised to be challenging (Ooi et al., 2016; Weitlauf et al., 2014). Research showed that mothers of autistic children exhibited high depressive symptoms related to more parenting stress (Alquraini et al., 2019; Weitlauf et al., 2014). This is especially true in contexts like the Saudi context in which children caretaking is dominantly handled by the mothers (Almansour et al., 2013; Hemdi & Daley, 2017;

Sulaimani & Gutt, 2019). This might be because fathers of autistic children may not have time to take part in caretaking.

Researchers investigated the quality of life (QoL) of parents of autistic children in the northern region in the KSA reported that female respondents had poorer QoL scores compared to males (Alenazi et al., 2020). However, researchers reported high levels of stress did not prevent mothers of autistic children from engaging in an intervention trial in Riyadh (Alquraini et al., 2019). According to Alquraini et al. (2019), mothers were able to carry out intervention strategies, and significant improvements were observed on maternal stress levels following an early intervention. It might be that participants in the Alquraini et al. (2019) received adequate levels of support, allowing them to engage in the intervention and carry out intervention strategies.

Moreover, parents' low levels of engagement in child's intervention may perhaps reflect their need to be supported more by professionals and family members (further discussed in Chapter 4). This issue was described by mothers of autistic children in the KSA (Hemdi & Daley, 2017). Semi-structured interviews conducted by Hemdi & Daley (2017) highlighted mothers' perception of the lack of support from professionals, spouses, and other family members. Researchers in the KSA suggested the need to establish and evaluate parental support services (Almansour et al., 2013; Altowairqi et al., 2015; Hemdi & Daley, 2017). Furthermore, researchers in the KSA suggested that professionals should consider the unmet needs of mothers of autistic children when designing interventions (Hemdi & Daley, 2017).

3.6.1 SLTs' Early Intervention Practice

The second aim of this PAR was to describe the treatment-as-usual provided by the SLTs in the EI practice and use the evidence to develop a consistent approach to intervention planning. The participating SLTs described the treatment-as-usual by developing an EI plan driven by their expertise and daily practice. The intervention goals followed the trajectories of language development (Table 3.2). Therefore, the findings suggest that the developmental approach is followed in treating autistic children in this context. However, it is important to spot that the language development milestones followed are those for English speakers. This may be justified by limited literature in Arabic language development. However, the participating SLTs were, to a large extent, close in the way they deliver the EI. The SLTs targeted similar intervention goals and followed the developmental approach but showed variation in the mode of delivery and the EI strategies used.

It is also worth noting that the SLTs' intervention plan lacks goals that primarily target joint attention and playing, with more focus on imitation and communication skills. These findings suggest that the SLTs may focus on goals that are core to enhancing the child's language and communication when working in a multidisciplinary team. Intervention goals such as joint attention and play are usually targeted by other team members, e.g., psychologists and OTs may therefore not need to be prioritised by the SLT team. This suggestion is consistent with what was previously proposed that disciplines within a multidisciplinary team often target intervention goals that lead to discipline-specific outcomes (Pecukonis et al., 2008; Strunk et al., 2017).

The study aimed to understand SLTs' experiences and EI practices and to describe the treatment-as-usual provided by the SLTs in this context. The participatory nature of the PAR enabled the SLTs to describe the treatment-as-usual and develop an intervention plan which will aid the development of the intervention program used in the feasibility study (further explained in Chapter 6). The study also brought insight into the challenges faced by the SLTs in engaging parents in the intervention and the factors affecting their intervention decisions.

Chapter 4: Action Research Study II

4.1 Introduction

Parenting an autistic child has been reported to negatively impact parents' well-being and quality of life (Ooi et al., 2016; Vasilopoulou & Nisbet, 2015). Parents of autistic children reported to have a lower quality of life compared to parents of typically developing children (Vasilopoulou & Nisbet, 2015). Parents, especially mothers of autistic children, consistently reported a high level of stress and depressive symptoms (Vasilopoulou & Nisbet, 2015; Weitlauf et al., 2014). Challenges faced in parenting an autistic child can arise from several factors such as care-taking responsibilities, lack of social support, inadequate services, financial constraints, and the label of autism (Ooi et al., 2016).

Dissatisfaction about autism services and difficulty accessing and navigating health systems was reported by parents of autistic children (Corcoran et al., 2015; Brewer, 2018). Several studies have investigated parents' experiences and perceptions of the services provided to their autistic children by ASD providers generally (Alnemary, Aldhalaan, et al., 2017; Salomone et al., 2016; Stahmer et al., 2019; Yi et al., 2020). However, few studies have focused on parents' perceptions of the services provided to their autistic children by speech language therapists (SLTs) (Auert et al., 2012; Mandak & Light, 2018). Researchers reported that SLTs' approaches to working with parents had clear implications in parents' experience of the intervention process and outcomes (Auert et al., 2012).

Parents faced challenges finding appropriate and effective SLT services for their autistic children (Auert et al., 2012; Mandak & Light, 2018). Previous studies investigating parents' experience of SLT services suggested that SLT's role was primarily focused on the autistic child rather than providing support to the family as a whole (Auert et al., 2012; Mandak & Light, 2018). For example, a study investigating the experience of 99 parents of autistic children indicated that less than half of participants felt that SLTs provided enough time to talk and only half of them felt they were treated as equals (Mandak & Light, 2018).

Lack of partnership between the SLTs and parents can impact parents' positive judgements of professional supports and services (Mandak & Light, 2018). Researchers highlighted the need for SLTs to provide more support to parents of autistic children (Auret et al., 2012; Leadbitter et al., 2020; Mandak & Light, 2018). Providing information and support is recommended to improve EI services (Alquraini et al., 2019). A systematic review and meta-analysis explored parents' perspectives in raising an autistic child recommended the use of a family-centred approach addressing and supporting the needs of the whole family and not just the autistic child (Ooi et al., 2016). Using a family-centred approach can empower parents to advocate for their child and subsequently reduce feelings of hopelessness about the child's improvement (Ooi et al., 2016).

Researchers reported key factors that influenced parents' feeling of empowerment in the therapy process, such as accessing therapy-related information, SLT-parent therapeutic relationship, and SLTs' facilitative style (Auert et al., 2012; Leadbitter et al., 2020). In addition, parents of autistic children indicated that SLT's personal qualities, such as the ability to build rapport with the child, active listening, and empathy, were directly linked to the success of the intervention program (Auert et al., 2012; Mandak & Light, 2018). Previous research investigating parents' and SLTs' perceptions emphasises the importance of clinician-parent relationships (Leadbitter et al., 2020; Ooi et al., 2016; Stahmer et al., 2019; Trembath et al., 2016). A strong clinician-parent alliance has been shown to improve clinical child and parent outcomes (de Greef et al., 2017).

The literature about the experiences of parents of autistic children about the services provided by SLTs has been conducted in Australia (Auert et al., 2012) and the United States (Mandak & Light, 2018). To our knowledge, previous studies conducted in the KSA have not addressed the experiences of parents of autistic children about the services provided by SLTs. Similarly, the published research addressing the experiences of parents of autistic children generally and with regard to the EI services is very limited. One study that investigated parents' perceptions of EI showed that parents of autistic children in the KSA have varied in their perceptions of the EI services (Alotaibi & Almalki, 2016). However, the participants expected to be involved and to be offered a more systematic intervention plan (Alotaibi & Almalki, 2016).

There has been research into parental stress related to raising an autistic child (Sahab & Balubaid, 2017) and strategies used to cope with the child's condition (Balubaid & Sahab, 2017) in the KSA. Researchers suggested lack of social understanding and professional support were the most reported causes of parental stress (Sahab & Balubaid, 2017). Several strategies were found to help parents cope with autism, such as spirituality, seeking family support, hiring assistants, and connecting with autism support groups (Balubaid & Sahab, 2017). Despite the progress, it is clear that parents' perspectives, expectations, and experiences of EI practices generally and those provided by SLTs in the KSA is not well-investigated.

4.2 Study Aims

Considering the parental role in EI, it is crucial to understand their perception of the current services to develop and enhance EI services. This study aims to describe parents' experiences and expectations related to the EI service provided in autism centre in Riyadh. The study is expected to give an insight into parents' experience in raising an autistic child, parents' perception about the services provided, including their involvement and their relationship with the child's SLT. Being aware of parents' needs will help the SLTs improve their service and provide the optimal support to parents when delivering EI in the upcoming feasibility study and their everyday practice.

4.3 Method

4.3.1 Research Context

The study took place in the speech language therapy (SLT) clinic based in the Autism Centre at Prince Sultan Military Medical City (PSMMC-AC) in Riyadh, KSA. PSMMC is a governmental hospital that provides services to armed forces personnel and other workers in the Ministry of Defence. The majority of the population served at PSMMC are Saudis. The SLT team at PSMMC-AC incorporates four speech language therapists (SLTs) at the time of data collection (more details about PSMMC-AC are provided in Chapter 3 Section 3.4.1).

4.3.2 Action Research Design

As described in Chapter 3, action research (AR) design was used to shape this study. AR is a recommended method for practice development research by healthcare professionals (Koshy et al., 2011; McNiff, 2016). What is distinctive about AR is the involvement of the people in the context where the research is being conducted, i.e., professionals and service users (Koshy et al., 2011; McNiff, 2016). When running AR, the action researcher must encourage feedback from the research participants and inform them about how the research is going (McNiff, 2016).

Different types and frameworks have been developed by action researchers in healthcare (Koshy et al., 2011; Meyer, 2000). For an AR aimed for improvements and change of intervention, the reflective process can be predefined, professionally led, conducted in the interest of research-based practice, and defined by professionals on behalf of and in the interest of service users (Meyer, 2000). Thus, the AR design will provide an understanding of the interests of service users, here, parents of autistic children. In addition, the AR will enhance SLTs' understanding of their own practice by reflecting on the experiences and interests of the parents.

4.3.3 Participants

The group included six Saudi mothers (MA, MB, MC, MD, ME, and MF) of autistic children (age ≤ 7.6 years). As shown in Table 4.1, participants' age ranged (26-40+). All participating parents were living in Riyadh at the time of data collection. All parents were married at the time of the study except (MD) was divorced. All participants have received at least 21 EI sessions (*M*= 25.6) by the SLTs in this context. Parents of autistic children (aged ≤ 7:6 years) receiving EI service by the SLTs at PSMMC-AC were approached. It was expected that parents of children aged ≤ 7:6 years would have a rich and recent experience of EI.

Table 4.1. Study II Participants' Demographics.

Participant	Age	Educational Level	Number of Children	Child's Age at Diagnosis	Child's Language Level	Number of SLT Sessions
MA	31-35	High school	2	2	Verbal (utterances)	23 in 36 months
MB	40+	Bachelor	6	< 3	Verbal (single words)	37 in 39 months
MC	36-40	Bachelor	4	5	Verbal (single words)	21 in 19 months
MD	31-35	Bachelor	3	2:6	Verbal (utterances)	30 in 17 months
ME	26-30	Bachelor	1	-	Verbal (utterances)	22 in 21 months
MF	36-40	Bachelor	3	-	Verbal (utterances)	21 in 20 months

Parents were approached in person during their regular follow-up visits at the centre and via email by the lead researcher and the SLTs. A brief description of the study was given along with the information sheet. Parents were asked to take the time and read it. They were asked to contact the lead researcher to express their interest in participating in the study either in person at the centre or via email. Employing a flexible approach of sampling until reaching data saturation is suggested in qualitative research (Boddy, 2016). However, this might not be possible in this study due to time restraints. Further. the ongoing recruitment of parents took around two months. A total of 12 parents were approached, ten at the centre and two via email. Out of them, six mothers agreed to participate, two refused, and four did not respond. All participants were informed about their right to withdraw at any stage of the study.

4.3.4 Data Collection

One-to-one semi-structured interviews with mothers were done by the researcher. The mothers were asked to describe their experience of raising an autistic child and being engaged in the intervention developed by the SLT. Parent's expectations about the EI services at PSMMC-AC were also elicited using a topic guide developed by the researcher. To improve the topic guide and increase SLTs' engagement in this action research, the SLTs were asked to review the questions and provide suggestions, if any. However, no changes were made to the initially developed topic guide (Appendix 1).

Throughout the interview, the researcher elicited parents' perspectives related to the availability and suitability of the EI services. The interview started with general questions about mother's experience in raising her autistic child and receiving autism services generally (not only intervention services) in Riyadh. Then, the mother was asked to describe her experience in PSMMC-AC in general and her experience in the SLT clinic in specific. After that, the mother was asked to talk about more detailed aspects of the service, such as the mother's role in intervention, her expectations about the EI and its outcomes, and suggestions to improve it. At the end of the interview, the mother was encouraged to add comments about any area that the researcher did not address.

The audio-recorded interviews and discussions were conducted at the PSMMC-AC meeting room using Sony ICD-PX370 Mono Digital Voice Recorder. The researcher began the interview by explaining the purpose and seeking consent to continue. Parents were encouraged to speak freely when answering and were told that their views of the service will not affect the services provided to their child in the meantime or the future. The interviews lasted between 20 to 55 minutes.

4.3.5 Data Analysis

Parents' interviews were transcribed for thematic analysis using the same method of Braun and Clarke (2006) as described in Chapter 3 Section 3.4.5. Verbatim transcription of parents' interviews was done by a research assistant. Transcriptions were completed between interviews to help determine data saturation. All transcripts from parents' interviews were checked by the researcher. Disagreements between the transcriber and checker were resolved through discussion and consensus. Data from parents' semi-structured interviews were coded line-by-line by the researcher following the same process explained in Chapter 3 Section 3.4.5.1. Since different experiences were expected to be exhibited by the parents, the codes were data-driven from each transcribed interview and manually generated whether or not similarity was found among the responses of other participants.

The interviews were conducted, transcribed, and analysed in Arabic. Then, the quotes were translated into English for supervision and use in this study. The translation was done by a certified English translator and the researcher. An in-depth analysis across participants was conducted at a later stage to develop more coherent codes. The researcher coded, reviewed, and refined the data under close supervision by Dr Loucas and Dr Knott. Initially, the data was analysed into 58 codes and five subthemes. The process of reviewing and refining the data led to the generation of five sub-themes and two core themes. Moreover, 16 codes were discarded, and 22 closely related codes merged together, ending with 20 codes (see Figure 4.1).

4.3.6 Reflexivity Statement

The research was conducted by a Saudi female who has no children, situated in the UK, and SLT who worked in the speech therapy team at PSMMC-AC. The researcher is a PhD student supervised by Dr Tom Loucas and Dr Fiona Knott (see Chapter 3 Section 3.4.6 for further details). Difficulties were experienced in analysing Arabic interviews under the supervision of English-speaking supervisors. Multiple meetings were held between the researcher and the supervisors to manage possible bias by reviewing the analysis rigorously. Two interviews were fully translated into English, and raw data (uncoded interviews) were shared with the supervisors to examine the coding process and help the researcher reflect on the analysis. However, the closeness of the researcher to the research setting may intentionally or unintentionally shape the analysis and interpretations of the interviews.

4.3.7 Ethical Approvals

This study has been reviewed and granted ethical approval by the University of Reading School of Psychology and Clinical Language Sciences Research Ethics Committee (Ethics no. 2018-060-TL) and PSMMC Scientific Research Centre Ethics Committee (Ethics no. 1073).

4.4 Results

Data from parents' interviews were analysed into two core themes: i) coming to acceptance and ii) parental engagement. As shown in Figure 4.1, each theme emerged from two to three subthemes. The themes reflected the parents' journey to accepting their children's autism and their experiences in receiving EI.

4.4.1 Coming to Acceptance

The first theme illustrated the parental journey from gradually recognising changes in their child's behaviours, searching for answers about what was happening, seeking

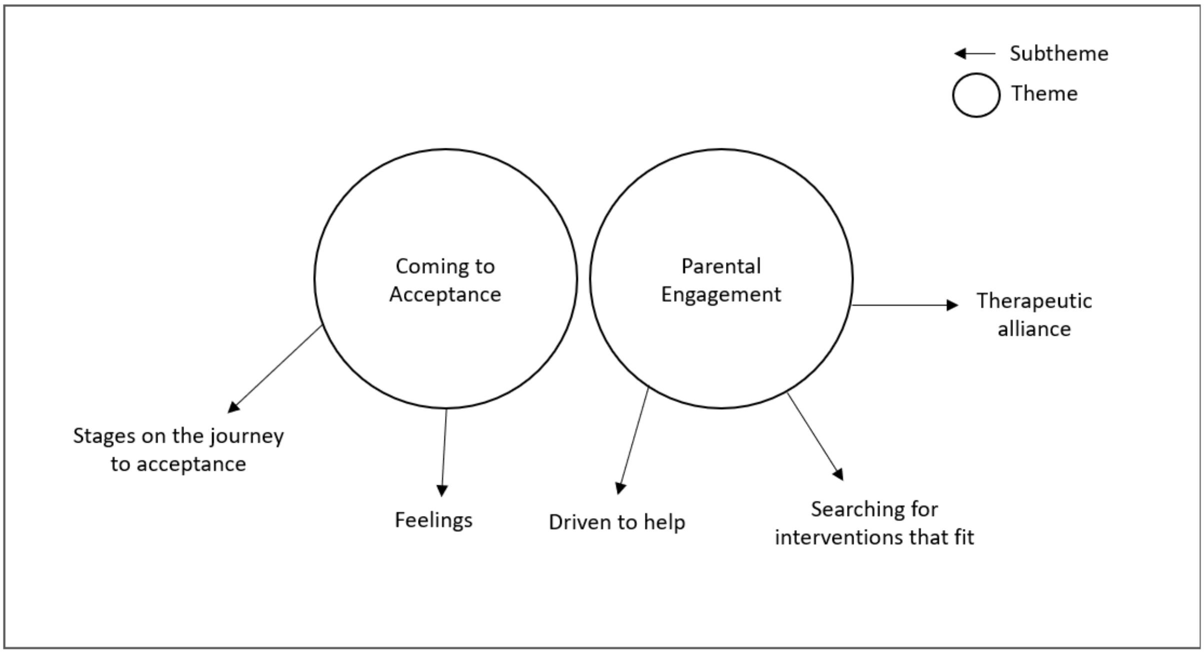

Figure 4.1. Thematic Map for Parents' Interviews.

professional help and getting a diagnosis to accepting the condition. Parents described their experience of this journey and their feelings on the way. This theme emerged from two subthemes: stages on the journey to acceptance and feelings. The two subthemes are intertwined in the data. However, separating parents' feelings from their experiences have added clarity when presenting the findings.

4.4.1.1 Stages on the Journey to Acceptance. The first subtheme is about multiple stages faced by the parents, from recognising to accepting autism diagnosis. Each stage was experienced by at least half of the participating parents. These stages included denial, searching for explanations, doubting the diagnosis, blame, taking action, and accepting autism condition. Initially, many participants reported denying that their child was different or might have autism *'People were telling us that he has autism and so, I was telling them that's not true, he doesn't have autism -MF'.* Participants reported noticing change or delay in child's behaviours, which made them search for explanations and answers by sharing their concerns with family and friends and by searching the internet *'It was my first time hearing about it, I immediately searched the internet and tried to read read read about it and what is it -MA'.*

Participants expressed a lack of knowledge about autism, and in some cases, they justified the delay in seeking professional help due to unawareness about autism features.

Moreover, the data reflected the efforts made by the parents to find answers. Participants sought medical advice by consulting specialised medical professionals at PSMMC and private clinics. In some instances, it required the parents to travel from their hometown to Riyadh to access diagnostic services. It also extended to requesting military job relocation to have continuous access to EI services. One participant reported postponing pregnancy until being satisfied with child's progress.

The interviews revealed uncertainty about the diagnosis which led participants to consult different medical providers. The reasons that contributed to this uncertainty about the diagnosis were not always clear. However, some participants linked their doubts to the lack of knowledge about autism and hoped to hear different diagnosis *'I was doubting, not doubting, but I wanted to take this idea out of my mind, I wasn't convinced, I thought if we train him or do something... -MF'*. Notably, the doubts and feelings reported by the participants did not prevent them from seeking professional help.

Parents' initial reaction and search for an explanation have expanded to self-blame and blaming others about what happened to the child, e.g., blaming houseworker or spouse. The participants blamed themselves and houseworkers for offering the autistic child long screen-time and short quality time. Blaming spouses and family members for the delay in seeking intervention was also expressed by the participants *'I talked to his father about his side-glancing that he might have a vision problem, his father got irritated because he [the father] has a vision problem and he believed I'm obsessed, so I ignored the issue -MC'*.

Parents varied in their attitudes toward accepting autism condition and its severity. Some participants reported acceptance of the child's condition. Other participants reported not accepting the diagnosis initially, and few reported a similar attitude at a later stage as their feelings and pain was reflected in the way they talk about autism. Further, differences were observed in the language used by the participants, e.g., MF referred to the condition with *'he has what is so-called autism'* and MB was avoiding the word autism *'At home, we don't want (child) to be having__ [participant was avoiding the word autism], we are trying our best to help her overcome it to be cured -MB'.* The data also revealed that some participants did not accept the differences between the autistic child and peers and wished for the situation to be transitory.

4.4.1.2 Feelings. The second theme emerged to cover various feelings expressed by the parents, such as shock, despair, frustration, worry, panic, and hope. Participants reported feelings of shock and despair after getting an autism diagnosis *'At the beginning, it was a shock, I don't know, I was hoping… because you know, we don't want it [autism] -MD'.* The participants' shock and despair feelings might be because of autism label and increased responsibilities, which was evident in the interviews. Moreover, MC reported being surprised by the number of appointments that were given to the child and linked her despair to increased responsibilities and difficulties in coping with the new situation *'At the beginning, he wasn't even able to utter 'Mama', I was in a great dilemma and stress due to their [her children] health conditions, work and other responsibilities; I wasn't able to cope with what was happening -MC'.* The quote also illustrated that this mother, MC, was hurt as she recognises child's traits.

The data also showed that the parents felt worried about the child, especially at the initial stage *'When I started, I was broken, I didn't know if he is going to get better or not, I didn't know -MA'.* One participant expressed worry about child's future and rights to have choices *'I don't want my daughter to be like a robot, I don't want, then she might be controlled by anyone, to be one of those who 100% obey the rules -MB'.* Being worried about child's progress and future might be attributed to panic, which was evident in the interviews ' *Many* *things improved (child name) 's attention improved, she started to notice when we enter the room, but she didn't talk, later we enrolled her in (EI centre) and (EI centre) and (EI centre), but nothing, now, (child) 's biggest problem is not being able to talk – MB'.*

However, participants reported positive feelings after noticing improvements in child's abilities and skills. This included a sense of accomplishment, relief, and hope for more progress *'I started to hope after seeing him producing speech with the therapists -MC'.* In addition, one participant mentioned a positive attitude toward the situation by believing that the child's condition was fated and destined '*First of all, praise be to God, we accepted this condition, Insha'Allah – MF*'.

In sum, the findings presented under this theme described parents' efforts and struggles before, around and after receiving autism diagnosis and their journey to accepting autism. Although parents mentioned positive feelings following child's progress, they expressed negative feelings more often in their interviews. It is important to recognise that positive feelings reported by the participants were mainly linked to child's progress.

4.4.2 Parental Engagement

The second theme reflected different aspects of parental engagement in EI, including their drive to help their autistic child, searching for interventions, and their perception about EI services in this context. This theme emerged from three subthemes: i) driven to help, ii) support that fits, and iii) therapeutic alliance.

4.4.2.1 Driven to Help. This subtheme reflected parents' motivation to engage in the EI and showed how some parents were desperate to help their autistic children. The subtheme also revealed parents' perspectives about being involved in the EI, their intervention priorities and how they communicated these priorities with the child's therapist. The interviews showed that parents were eager to engage in the EI provided to their autistic child and described motivators that fuelled them to seek and continue receiving EI. Some participants reported seeking EI services to avoid regret at a later stage and not because they believed it would help their child *'...Initially, I tried to convince myself that I should attend the appointments so that, in the future, I would not regret not taking the chance of trying the services provided here, so it was -MF'.*

Further, the reason behind low or no expectations that their child will benefit from EI were lack of knowledge, underestimating child's SLT *'I didn't expect that the therapist is this good, I convinced myself that I'd try the services here and there is nothing to lose; if my child didn't improve, I'd simply take him to another clinic – MA',* and child's age and skills '*You know, at the beginning if I told you I didn't expect even 1% that he will respond to me.. because he wasn't producing not even a single word, not even a single word! - ME*'. Parents have also reported their child's progress as a motivator to continue EI sessions.

Parent's drive to help led some parents to recruit family members, i.e., siblings, to assist in increasing the intensity to reach EI goals. One participant reported a feeling of overwhelming her child by the amount of intervention the child is getting. Overcompensation was present in a parent's comment of being aware of applying EI methods that are not evidence-based to try everything to help her autistic child. The data also revealed that overcompensation extended to prioritise the autistic child and his needs over the siblings *'After we recognised_ suspected that (child name) has a problem, she became number 1 at home. In this way, I felt that we caused a problem to ourselves that (child) used to this way with everyone -MB'.*

Participants expressed how good it was to be involved in EI and take a vital role in the child's improvement. Participants reported being empowered because EI opened the door to their understanding of how and why it was essential to achieve specific skills *'I feel it's better than when I'm behind a window watching them because when I'm only observing, there are* *things that I don't know why the therapist did it... it might be an essential step and important, but I miss it just because I don't understand -MB'.*

The parent's drive to help was observed in their efforts to make the most out of the EI plan. Participants cared about and prioritised some skills over others based on their perception of what is vital to the child and family. Spoken language was of most importance to the participants, especially MB, who reported this to be a significant issue in four instances *'I feel the most thing (child) lack is speech, so I read and search about speech only -MB'.* Participants also reported social inclusion and bringing the autistic child's abilities in line with those of typically developing children. Moreover, MB reported following her own judgment even if it contrasted with the professional's judgment and intervention plan. Although MB was not referring to the child's SLT in this matter, this finding highlights the importance of addressing family needs when planning an EI program.

However, parents described how difficulties in transportation, finance, and job inflexibility created challenges in engaging in EI. MC expressed feeling under pressure and being emotionally exhausted due to increased responsibilities' *...In the beginning, it was more of a mental exhaustion than physical exhaustion; I was busy with my work, my children's schools and academic performance, appointments [for the four children], household requirements, and I had to sit and spend some time with him. It was a huge dilemma -MC'.* These findings indicate that parenting a child with ASD may affect the quality of life of the mothers and can alter major life decisions, i.e., getting pregnant or having a job.

4.4.2.2 Searching for Interventions that Fit. This subtheme describes the efforts made by the parents to find the right intervention and support for their autistic child. Parents had different views about the EI services, described increased responsibilities, and reported difficulty transitioning from EI to school settings. Most participants were satisfied with the outcomes from the EI provided by the SLTs at PSMMC-AC *'I can see he benefitted much from speech and communication -MD'.*

However, some participants reported dissatisfaction with the intensity of SLT and OT sessions generally and lack of ABA specialists. In addition, MB was unsatisfied with the EI outcomes, specifically verbal language outcomes *'I wished for more_ I feel that the SLT knows how to deal with (child name), I felt that if she had the chance to spend more time with her, she could've talked – MB'.* Dissatisfaction with the outcomes of the EI led participants to seek many service providers to meet the child's needs. Some participants reported following with two speech therapists in parallel to get more professional time. This finding may also signify parents' drive to help their autistic child, as expressed earlier in this theme. However, seeking additional services in private clinics added burdens to one of the participants due to the cost of EI sessions.

Most participants reported difficulties in searching for a suitable educational setting. Some participants described this process as disappointing and very challenging. Participants searched for settings with classmates matching the child's level and not far from their homes. Some participants were concerned that their child may develop inappropriate behaviours if she or he was in a setting with autistic children with more severe traits *'What I'm going to do in the near future is enrolling him in a mainstream school because my child's case doesn't require a special setting, he might develop inappropriate behaviours -ME'.*

4.4.2.3 Therapeutic Alliance. This subtheme summarises parents' perspectives about the parent-professional relationship, such as collaborative nature and trust. It also reflected the importance of SLT's attributes on parent's engagement in intervention. Participants showed a sense of gratitude to the professionals at PSMMC-AC. Participants were grateful for professionals' collaboration which exceeded their expectations. MA acknowledged effective communication with the SLT, i.e., for being offered direct contact via email. MC described professionals' collaboration in this context as peerless, and MD appreciated being seen during SLT's break time *'God bless her (SLT), she was giving my child appointments during her break when there is no available slot, she was asking me to come at 12 pm, I wasn't aware it was during her break. -MD'*

The interviews reflected the importance of gaining parental trust when delivering EI services. For example, MB reported feeling worried and disappointed from broken promises by professionals outside PSMMC-AC. An EI therapist promised the participant positive changes in the child's behaviours within a period of time, but no differences were seen *'I like the service here, for me, there is one important thing; I trusted (SLT), I feel that.. I don't know because it is governmental, I am one of those who thinks that here is trustworthy, they have trusted certificates.... they have experience, they get continuous training, their education did not stop by getting the degree'.*

Professional's attributes have motivated the parents to continue receiving EI in this context. For example, basic gestures like smiling or accompanying the child from the waiting area to the therapy room meant a lot to the participants *'I swear to God you won't imagine how impressed I am with the doctors and the specialists, from the moment I enter the centre until I leave, I see them smiling, although autistic children are very difficult, sometimes their families can't handle their behaviours -ME'.*

Moreover, MB reported discontinuing previous EI services because of negative experience with service providers '*They have this stereotyped idea that parents do not make efforts, that parents do not do what they're supposed to do... also, I don't like the way they do things, but they don't accept criticism, for example, they want my child to sit down during the session, this was a nightmare, I left them because of this- MB'.*

In sum, parents' views about EI services in PSMMC-AC and Riyadh generally were mixed. The participants faced challenges in supporting their autistic child, and some of them were desperate to get more social and professional support. Finally, the data reflected that good professional-parent relationships and professional's attributes were greatly valued by parents of autistic children in this context.

4.5 Discussion

The study investigated the experiences of Saudi parents of the EI service provided by the SLTs in PSMMC-AC. Understanding parents' experience is fundamental to enhance the EI services provided to autistic children and their families at PSMMC-AC. The data provided an understanding of parents' perspectives and expectations with regards to the EI services and professionals in this context. The findings also reflected the emotional impact of receiving an autism diagnosis and parenting an autistic child on parents, specifically mothers.

The study findings brought evidence that parenting an autistic child in the Saudi context was challenging and effortful. Parents face care-taking challenges in raising an autistic child in several cultures (Altiere & Von Kluge, 2009; Meirsschaut et al., 2010; Weitlauf et al., 2014). Parenting autistic child has been reported to cause negative feelings such as stress, depression, and anxiety symptoms in many cultures (Bonis, 2016; Corcoran et al., 2016; Vasilopoulou & Nisbet, 2016). It is not uncommon that parents of autistic children encounter negative feelings of shock, frustration, and elevated distress after getting an autism diagnosis (Crane et al., 2016; Dale et al., 2006; Weitlauf et al., 2014). Congruent with previous studies, the parents expressed negative feelings often in their interviews. The parents exhibited negative feelings like shock, despair, and worry, especially after getting the diagnosis. In addition, the interviews revealed that some parents doubted the diagnosis before coming to acceptance and others wished for the situation to be transitory.

The interviews revealed that not all parents noticed that their child was different. Some parents reported being informed by others, e.g., family members or friends. In both cases, parents struggled to search for explanations, and some were confused about the child's traits and searched for an alternative answer. This finding is similar to previous reports of questioning autism and searching for explanations by parents of autistic children in the US and Belgium (Altiere & von Kluge, 2009; Meirsschaut et al., 2010). Furthermore, the data brought evidence that some parents were in denial at the beginning of their journey and have reported denying autism in front of others. In line with the study findings, denying autism condition amongst parents was highlighted in previous research in the US and Saudi Arabia (Corcoran et al., 2015; Hemdi & Daley, 2017). Although the reason behind the parent's tendency to deny autism in front of others was not apparent in the interviews, it may possibly reflect a fear of the social stigma attached to the diagnosis and its effect on the child and family (Broady et l., 2017; Corcoran et al., 2015).

Negative feelings exhibited by the parents might be due to a lack of knowledge about autism and its impact on the child and the family, which was evident in the interviews. Lack of understanding autism has been reported by parents of autistic children in the KSA and other contexts (Hemdi & Daley, 2017; Ooi et al., 2016). Moreover, because the participants in this study were all mothers, it is possible that they exhibited negative feelings and were overwhelmed because mothers in the Saudi culture assumed most responsibility to the care of their children. Similar observations of lack of support at home were reported by mothers of autistic children (Bilgin & Kucuk, 2010; Hemdi & Daley, 2017).

The data suggests that all parents struggled to accept autism. However, some parents proceeded on their journey to accepting autism faster than others. Similar findings have been reported by Ooi et al. (2016). Further, some parents exhibited self-blame or blaming others for what happened to the child in their way to acceptance. Previous research suggested that the mother's feeling of self-blame can persist for 18 months after getting the diagnosis (Da

Paz et al., 2018). Moreover, researchers concluded that reduction in self-blame was a strong predictor of parental adjustment and psychological resilience (Da Paz et al., 2018).

Congruent with previous studies, parents encountered difficulties supporting their autistic children like increased responsibilities and difficulties in transportation, finance, and job inflexibility (Corcoran et al., 2015; Ooi et al., 2016; Stahmer et al., 2019). Working parents face unique challenges when it comes to attending regular in-clinic intervention sessions. Researchers reported that parenting an autistic child can lead to job loss or decreased working hours in the Saudi culture and other contexts (Alnemary, 2020; Cidav et al., 2012). Reduced working hours can lead to financial difficulties described in parents' interviews and reported by previous reports (Alnemary, 2020). These difficulties were associated with emotional exhaustion, mainly when parents reported a lack of family support.

Overall, the data suggested parents' experience of EI services provided by the SLTs in this context was positive. Parents were generally satisfied with the intensity and outcomes of the EI. However, some parents wished for more one-to-one EI sessions, and one participant was dissatisfied with the EI outcomes. Therefore, the parents reported seeking additional services to the services provided by the PSMMC-AC team to get more professional time and hopefully better outcomes. Previous studies count the intensity of intervention by the professional time spent by the clinician in training the child or the parent (Linstead et al., 2017; Nevill et al., 2016). Although researchers suggested that higher EI intensity led to better outcomes (Klintwall et al., 2015), research showed that EI program using as low as two hour/bimonthly of professional time led to a long-term reduction in autism features (Pickles et al., 2016). The findings reflect a tension between what parents want and what may be available because of resource limitations.

The theoretical approach behind low-intensity EI programs is the parent's active involvement in the intervention by practising the EI strategies daily with their autistic child

(Pickles et al., 2016). However, parents differ in their capability to carry out EI strategies that have been taught in their daily interaction with the child. Thus, this finding highlights the value of informing the parents about evidence-based practices and involving them in the decision-making process. Previous research highlighted the need for parents of autistic children to have clearly explained roles by the SLT to know what to expect from the EI (Auert et al., 2012). The findings from this study showed that parents of autistic children highly valued the collaboration of SLTs in this context. Therefore, researchers suggest that all decisions must be made in partnership with parents and addressing family needs (Mandak & Light, 2018).

The data provided an understanding of parental engagement in the EI provided to their autistic children. All participants were eager to help their autistic children and showed substantial efforts to improve their child's behaviours. However, some parents reported that their drive to help their child was fuelled by fears of regretting not doing so and not because they believed the child would improve. It is unclear why parents in this context did not expect to benefit from the EI services provided. However, it is possible that parents' low expectations were due to a lack of understanding of autism and EI benefits. In addition, some parents expressed being overwhelmed and exhausted, which may lead to feeling hopeless about child's benefitting from the intervention.

Mothers' remarks about therapeutic alliance highlight the importance of the professional-parent relationship for the parents of autistic children. The findings suggest professional's attributes and collaboration are vital for continuous parental engagement in EI. Similarly, a strong professional-parent alliance has been shown to significantly associate with improved clinical outcomes and treatment engagement (de Greef et al., 2017). Furthermore, the interviews showed trust is a critical element of this alliance. Congruent with these findings, researchers suggested that professional's support and trust led to a smooth path to autism services (Altiere & von Kluge, 2009; Stahmer et al., 2019).

The data also brought insight into the challenges faced by parents during a vital stage in the child's learning, inclusion into schools. The parents demanded support in finding an educational setting that suits the child's needs. Specifically, parents were looking for a school with classmates matching the child's level and not far from their homes. In the KSA, the Ministry of Education introduced the Regulations of Special Education Programs and Institutes (RSEPI) in 2001 (Alquraini, 2013). The RSEPI emphasises that students with disabilities should be educated in general education and that each individual with a disability is eligible for an individual education plan developed by a multidisciplinary team, including the parents (Alquraini, 2013).

Although there is significant progress in the special education services in the KSA over the past 50 years, researchers pointed out that the implementation of RSEPI policies is limited (Aldabas, 2015; Alquraini, 2014). Therefore, it is likely that the parents faced challenges in selecting the appropriate educational setting, if available. Similar findings have been observed in other contexts. For example, a meta-analysis of 50 papers conducted in 13 countries, including the KSA, suggested that most parents of autistic children were dissatisfied about their child's inclusion into the school (Ooi et al., 2016). The finding suggests that parents of autistic children need more professional support that addresses their concerns about the child's future success (Ooi et al., 2016).

The study explored parents' expectations and experiences of the EI services in Riyadh. Besides parents' perception of the EI services, the data provided insight into their experience raising their autistic child. The parents described the challenges of the journey to acceptance and a lot of positive experiences with the SLTs, highlighting the importance of therapeutic alliance. This provides a steppingstone for the SLTs to change and improve in practice in this context.

4.6 Action Research General Discussion

This action research described in studies I and II aimed to evaluate current EI practices provided by the SLTs at PSMMC-AC by understanding the experiences of both the SLTs and parents of autistic children. Describing SLTs' and parents' experiences helped understand their needs and identify areas of improvement in line with current evidence-based practice. The AR provided insight into the current EI practice, which is expected to help select and develop EI programs and improve service delivery models in this context.

In Study I (Chapter 3), the PAR enabled the SLTs to describe their EI practices, share their views of the practice, and discuss the challenges faced in delivering EI. The findings from Study I showed that the intervention provided by the SLTs was therapist-implemented or hybrid, provided on a one-to-one basis, with no consistent parent training. The findings from Study II helped understand parents' experiences and perceptions not only of the EI but also of parenting an autistic child. The study showed that parents of autistic children have mixed views about EI intensity and outcomes. The study also reflected the challenges faced by parents in supporting their autistic children in this context.

In this AR, the participating parents were known for their willingness to attend the EI sessions and were actively involved in the intervention as reported by the SLTs and reflected in the number of EI sessions attended (Table 4.1). However, not all of the participating SLTs were involved in delivering the EI to the participating parents. Due to the lack of pair-matched participants, it is impossible to directly compare the SLTs and the parents in this study. However, the two studies provided an opportunity to compare and reflect on the experiences of both groups.

The findings from SLTs' interviews suggest that there is agreement among the SLTs that engaging parents in the EI was challenging. It is evident from the data that the SLT's expected the parents to be more involved in the implementation of the EI. On the other hand, the findings from parents' interviews reflected that receiving an autism diagnosis and caring for an autistic child negatively impacted parents' emotions and well-being. Parents varied experiences and personal coping resources will affect how they evaluate the services and engage in the EI as reflected in their mixed perceptions.

The findings suggest that the mismatched expectations between the SLTs and parents of autistic children about the parent's role may interfere with delivering the EI in this context. Congruent with these findings, other researchers have reported that parents of autistic children and professionals had different views about parent's engagement (Stahmer et al., 2019). According to Stahmer et al. (2019), family challenges were perceived as a lack of engagement by autism professionals. These findings underline parents' need for more support by the SLTs alongside the intervention to understand child's abilities, understand the benefits of parent-child interaction, inform parents about evidence-based interventions, empower parents by actively engaging them in the decision-making process, and have realistic expectations for EI outcomes.

Researchers have highlighted the importance of managing parent's expectations about the role of the SLT and the pace of developmental change at an early stage (Leadbitter et al., 2020). In acknowledging that parents of autistic children come with different expectations and experiences, SLTs reported the importance of not assuming and instead actively working to ascertain parent's knowledge, competencies, motivation to get involved, and need for information (Trembath et al., 2016). Moreover, researchers recommended that the SLTs and parents discuss their roles and responsibilities so that the EI is conducted in a collaborative manner (Auert et al., 2012).

Furthermore, researchers reported that parents of autistic children face challenges in dedicating time to attend intervention sessions and carry out intervention strategies (Corcoran et al., 2015; Leadbitter et al., 2020). In this regard, the study revealed that parents' ability to attend and engage in therapy sessions was affected by job inflexibility, transportation difficulties, and increased responsibilities. Congruent with this finding, researchers reported that barriers such as job inflexibility, transportation difficulties, and increased responsibilities impacted parents' ability to access services and engage in the intervention (Stahmer et al., 2019).

The findings emphasise the need to address these practical barriers to enhance parents' engagement and accessibility to EI services. For example, to address transportation barriers and lack of involvement due to job inflexibility or family obligations, healthcare providers may consider providing parents with the opportunity to engage in EI remotely. Telemedicine models have successfully engaged parents of autistic children (Ferguson et al., 2019; Unholz-Bowden et al., 2020). Researchers also suggested supporting the parents by providing access to intervention sessions on evenings (Stahmer et al., 2019).

Action research is recommended to evaluate whether the current practice is as good as the providers would like it to be, identify areas of improvement, and find ways to improve them (McNiff, 2016). This AR has enabled the SLTs to describe the EI practice and identify areas of improvement by reflecting on parents' experiences and perceptions. The findings from both studies showed that at least a subgroup of parents of autistic children wanted more EI sessions, i.e., one session or more per week. These findings will help to decide the intensity of the EI program used in the future feasibility study. For example, it might be worth investigating the practicality of providing parents with one session per week instead of a less intensive EI plan, i.e., current practice.

The findings brought evidence that parents in this context made substantial efforts to help improve child's autism behaviours. In addition, the data revealed that parents valued the professional-parent therapeutic alliance and indicated it was vital for continuous engagement in EI. These findings support the plan to further investigate the feasibility of engaging parents of autistic children in a parent-mediated early intervention program in this context (see Chapter 6). Finally, the AR provided a structure and direction to improve community-based practices, i.e., identifying the areas that require enhancements for optimal support to parents of autistic children in the Saudi context (for further discussion, see Chapter 6).

4.6.1 Limitations

The study is the first to investigate the experience of Saudi SLTs in delivering EI and one of the very few studies examining the experiences and perceptions of parents of autistic children in the KSA. One of the unique characteristics of AR is its context-specific and situation-based nature. This AR was specifically designed to help develop a parent-mediated early intervention program in light of current EI practices in this context to be used in the upcoming feasibility study. Thus, it is difficult to generalise study findings on a broader population of parents and SLTs caring for autistic children.

However, these findings may be helpful to understand and draw a conclusion about a similar local context or population. Although the results must be treated with caution when drawing conclusions about the population, the study brought evidence of many similarities with previous literature. The findings suggest that, similar to other contexts, raising an autistic child in the Saudi context was a challenging process for the parents. The challenges faced by parents and the professional-parent relationship played a role in parent's engagement in the intervention. Similar findings have been reported (Corcoran et al., 2015; de Greef et al., 2017; Leadbitter et al., 2020).

It is important to mention that the participating parents in this study were known for their willingness to attend intervention sessions and were actively involved in the intervention plan as reported by their SLTs. The researchers paid attention to recruiting less engaged parents and parents who have made efforts to carry out intervention strategies. However, some of those parents refused to participate, and others agreed but missed the interview without prior notification. Therefore, the findings may not provide a balanced perception of the SLT service. In addition, it might be possible that parents did not speak openly during their interview, considering that the researcher was involved in the service.

The AR design was used in this study in which the researcher had a predetermined agenda and sought collaboration to develop the intervention plan and identify areas of improvement. AR was chosen because it provides a democratic and collaborative framework to improve practice. Moreover, the AR encourages the involvement of the participants in all research stages. However, the SLTs decided not to be involved in the thematic analysis of parents' data. It was acknowledged that the participating SLTs are practising clinicians and may not have spare time to participate in all the stages of this AR project. In addition, parents were not involved in all stages due to constraints in time and resources, i.e., parents have no prior experience in this type of research and thus, require training.

Finally, considering that the approach followed in treating autistic children in this context is a multidisciplinary approach, it is essential to highlight that this AR is discipline-specific, i.e., it was conducted by SLTs and mainly focused on speech therapy services. Therefore, study findings may provide evidence about a narrow breadth of the whole continuum of care in this context.

Chapter 5: Feasibility Study Part I

5.1 Overview

Feasibility studies are used to assess whether an intervention is worth further full-scale testing to investigate its efficacy, e.g., using randomised controlled trials (Bowen et al., 2009; Tickle-Degnen, 2013). Feasibility studies are expected to save time and cost if conducted carefully before large clinical trials (Orsmond & Cohn, 2015). The United Kingdom's National Institute for Health Research (NIHR, n.d.) has defined feasibility studies as "pieces of research done before a main study in order to answer the question 'Can this study be done?'.

In Chapter 3, the EI practice, i.e., treatment-as-usual delivered by the SLTs at PSMMC-AC was defined using the PAR. Considering the nature of the qualitative method used in the PAR, it helped in describing and developing the early intervention (EI) program and was not designed to answer questions related to the effectiveness of the EI in PSMMC-AC. However, researchers suggest investigating the feasibility and preliminary effectiveness of the intervention program delivered via telemedicine are necessary to justify conducting a large-scale clinical trial (Bearss et al., 2017). Given that the effectiveness of the EI practice in this context has not been addressed using RCTs before the time of this project, it is sensible to establish the feasibility of the approach used first. Moreover, researchers reported that a feasibility study might be indicated when there are few previously published papers, or there is no existing data about the intervention (Bowen et al., 2009).

Some of the areas of focus for feasibility studies are acceptability, demand, implementation, practicality, and usability (Bowen et al., 2009). Evaluating recruitment capability, data collection procedures, and outcome measures are also key objectives in feasibility studies (Orsmond and Cohn, 2015). This chapter and the next aimed to investigate parental acceptability and intention to use telemedicine and video-feedback method in the Saudi context. The study will examine the practicality of the telemedicine platform and the implementation of the outcome measures. The study will also investigate the usability of coaching caregivers via telemedicine in this context. Part I was conducted before delivering the intervention (Part II) to develop and evaluate the procedures and resources planned to be used in the intervention.

5.2 Introduction to Acceptability of Telemedicine

Although the KSA is one of the first countries in the Middle East to adopt telemedicine services in 1990, slow progress was observed over the years (AlSamarraie et al., 2020). Systematic reviews suggested that poor adoption of telemedicine in the KSA could be a result of individual, organisational, technical, financial, and legislation barriers (Alaboudi et al., 2016; AlSamarraie et al., 2020). A longitudinal study of factors affecting telemedicine services' sustainability concluded that usability of telemedicine platform and acceptance of professionals and patients fostered its sustainability (Segato & Masella, 2017). Thus, understanding the acceptability of telemedicine is essential to develop a sustainable telemedicine service (Segato & Masella, 2017).

A systematic review of barriers and challenges in adopting telemedicine services in the KSA revealed that different healthcare sectors within the KSA, e.g., Ministry of Health, Military, and private sectors, are likely to face some common barriers, yet significant variation between healthcare sectors was also reported. To our knowledge, the literature on patients' perspectives toward telemedicine and barriers to adopting telemedicine services at PSMMC is limited. A study investigated the perceptions of 101 professionals working at PSMMC who utilised telemedicine in their clinics found that 88% of the professionals reported patients' acceptance of telemedicine (Alnasser, 2017). However, the study also found that 73% of professionals who used telemedicine reported that their patients were ‘slightly worried’ about their privacy while using telemedicine (Alnasser, 2017).

Findings from a systematic review suggested a number of challenges in utilising telemedicine services in the region, e.g., technological, organisational, and cultural barriers (AlSamarraie et al., 2020). According to AlSamarraie et al. (2020), adopting telemedicine in Middle East countries, including the KSA, was strongly influenced by cultural and religious barriers. Researchers identified five cultural and social barriers: religious and social restrictions, resistance to change, traditional beliefs, literacy level, and language barrier (AlSamarraie et al., 2020). Researchers concluded that religious and social restrictions are the most common challenges facing telemedicine adoption in countries like the KSA and Iran (AlSamarraie et al., 2020).

Furthermore, researchers reported that cultural barriers are a greater issue than technical barriers for telemedicine use by clinicians and clients in two Middle Eastern countries, i.e., Jordan and Syria (Alajlani & Clarke, 2013). Researchers suggested that it might be that clinical staff, especially female clinicians, are often averse to being video-recorded due to concerns about data protection (AlSamarraie et al., 2020). Findings from the systematic review revealed that 21% of the previously published research on perceptions, attitudes, and barriers toward using telemedicine in the Middle East was conducted in the KSA (AlSamarraie et al., 2020). However, this area needs to be further examined because the review revealed that researchers mainly investigated professionals and stakeholders’ perspectives toward the use of telemedicine in the KSA and service users’ perspectives were not considered (AlSamarraie et al., 2020).

Parents’ acceptance of telemedicine as a mean of service delivery and to participate in future research utilising telemedicine is important to succeed in the intervention. Sharing real-time or previously recorded audio or video materials of parent-child interaction with the therapist to receive feedback may not be accepted by some parents (see Chapter 1 Section 1.5.3.1.2 for details about coaching parents via telemedicine). This is particularly important in the Saudi culture, where families are concerned about their privacy and religious beliefs. In some families, the cultural and religious beliefs may prevent the females/mothers from sharing a video-recorded material without face-cover worrying it might be seen by a male therapist. A survey completed by 393 Saudi females revealed that when removal of face-cover is required, only 28% of respondents will allow a male physician to examine them (Alqufly et al., 2019).

The issue of video-recording mother-child interaction was reported in a previous feasibility study done by Alquraini et al. (2018) in Riyadh. Researchers reported that most of the participating mothers expressed extreme hesitancy to being videoed after giving their consent to participate in the study. To solve this matter, Alquraini et al. (2018) reported modifying the method by using a live-observation checklist to evaluate mother-child interaction. Moreover, face-cover would have made any assessment of the non-verbal communication between the mother and her autistic child extremely difficult. In addition, it may potentially affect child interaction as it is not the usual way of communicating at home. Therefore, parents' acceptability of the method is vital to determine whether the intervention can be conducted in this context.

Surveys are a common method in telemedicine research for assessing parents' preferences, attitudes, experience, and satisfaction (Langbecker et al., 2017). Researchers used survey methods to assess telemedicine perceived usefulness, perceived ease of use, and intention to use by professionals and patients (Gorst et al., 2014; Hu et al., 1999; Langbecker et al., 2017). For example, the Technology Acceptance Model TAM-21 (Hu et al., 1999) is a validated and reliable tool used to capture both professionals' and patients' attitudes toward telemedicine.

Using existing validated survey tools rather than developing new measures is recommended, where possible (Langbecker et al., 2017). However, to our knowledge, there was no valid and reliable survey tool that measures patients' attitudes toward using telemedicine developed in the Arabic language at the time of this study. Careful adaptation and piloting of telemedicine survey measures, e.g., TAM-21, is advised to ensure its suitability to the tested population (Langbecker et al., 2017). Adaptation of an existing measure may include translating the survey into a different language, changing the wording of survey items, selecting specific items, and using different response options (Langbecker et al., 2017).

In conclusion, this work completed prior to implementing the telemedicine intervention aimed to investigate the acceptability of parents of Saudi autistic children to use telemedicine using an intention to use questionnaire (ITUQ). The study will explore parents' acceptability to participate in future telemedicine studies. It will also investigate gender differences in telemedicine acceptability and intention to use.

5.2.1 Part I Aims

- To investigate parental acceptability to receive early intervention via telemedicine in the Saudi context.
- To investigate parental acceptability to participate in future studies utilising telemedicine and video-feedback method in the Saudi context.
- To investigate how likely parents in the Saudi context are to use telemedicine.
- To investigate if there is a difference in telemedicine acceptability and intention to use between Saudi males and females.

- To test the practicality of delivering parent-mediated early intervention remotely via videoconferencing.
- To develop a behavioural observation measure of parent-child interaction.
- To establish reliability for the developed parent-child interaction measure.

5.3 Method

5.3.1 Design

A self-administered survey design was chosen to determine the intention to use (ITU) and acceptability to participate in future telemedicine trials among PSMMC-AC service users. Surveys have been widely used for assessing patients preferences and attitudes in telemedicine research (Langbecker et al., 2017).

5.3.2 Participants

To investigate study aims, the Intention to Use Questionnaire (ITUQ) was completed by 47 parents of autistic children, 66% females and 34% males (31:16). 89% of the parents who completed the questionnaire lived in Riyadh, and 11% outside Riyadh. Parents of autistic children (aged <16 years) were approached at PSMMC-AC to complete the ITUQ. The recruitment process involved approaching the parents at the waiting area at PSMMC-AC. Participants were asked if they were happy to complete an anonymised survey about their intention to use telemedicine services and participate in future studies. Participants gave consent to participate by completing a paper copy of the survey. The ITUQ was collected by research assistants from the mid of January 2019 for four months.

5.3.3 Materials

The acceptability of telemedicine delivered EI was evaluated using the Intention to Use Telemedicine Questionnaire (ITUQ), which was completed by PSMMC-AC service users. The following sections provide a description of the ITUQ development and content.

5.3.3.1 ITUQ Development and Content. The ITUQ was developed for the purpose of this study to investigate the acceptability for telemedicine services, i.e., how likely the telemedicine will be used. It was developed from the Technology Acceptance Model (TAM-21) (Hu et al., 1999) and the Telehealth Acceptance Measure (MALT-TAM) (Gorst et al., 2014). TAM-21 consists of 21 items designed to investigate the perceived usefulness, ease of use, attitudes, and intention to use telemedicine by both professionals and patients (Hu et al., 1999). The MALT-TAM is a 10-item measure that investigates patient's feelings and motivation to use telemedicine, including the extent to which individuals perceive that people who are important to them want/approve their use of telemedicine services (Gorst et al., 2014). Some of the TAM-21 and MALT-TAM items have been used or modified based on their suitability to the study objectives. Additional items were also developed to investigate how likely parents are to participate in future telemedicine trials.

As shown in Table 5.1, the ITUQ is a 13-item questionnaire. After a brief lay introduction about telemedicine and the research project, respondents were asked two yes/no questions related to their previous experience of telemedicine (see Table 5.1 Section 1). The remaining 11 questions answered on a five-point Likert scale (where 5= strongly agree, 4= agree, 3= neither agree nor disagree, 2= disagree and 1= strongly disagree) were divided into two sections. Section two included six items to investigate respondents' intention to use telemedicine service, if available. It aimed to elicit parents' perspectives about telemedicine, i.e., whether they think that telemedicine is suitable and beneficial in serving their autistic child or not. The final five items aimed to investigate respondents' willingness to participate in future studies that involve receiving intervention via telemedicine. It also addressed the cultural consideration of the acceptability to mothers of sharing video-recorded parent-child interaction.

Table 5.1. Intention to Use Questionnaire Items (the Arabic Version is provided in Appendix 4).

Section 1- Previous experience.	1. I have heard about telemedicine before. 2. I have used telemedicine services before.
Section 2- Intention to use.	3. Using telemedicine in patient care is a good idea. 4. I believe telemedicine could be beneficial to my child's care. 5. I intend to use telemedicine in my child's care when it became available. 6. I believe I have the ability to use telemedicine to support my child. 7. People who are important to me would approve of my using telemedicine. 8. When confidentiality is guaranteed, I would be happy to use video of me and my child with the therapist as part of telemedicine.
Section 3- ASD telemedicine trial.	9. I would be interested in taking part in research involving testing telemedicine in early intervention for ASD. 10. I would be happy to share a video with the research therapist in the telemedicine session. 11. I would be happy to share a video with the research therapist and a second researcher in the telemedicine session. 12. I will allow the research therapist to store the video for later viewing. *Note: the video will be destroyed after viewing.* 13. I will allow the research therapist to store video for later viewing with a second researcher. *Note: the video will be destroyed after viewing.*

5.3.3.2 ITUQ Translation and Pilot Testing. The questionnaire was developed in English and translated into Arabic by three undergraduate students, members of the Speech and Hearing Student Club at King Saud University, Riyadh. A forward-backwards translation method was used following the Mapi approach (Acquadro et al., 2004). Two students worked individually on the forward translation to create two Arabic versions of the ITUQ. The students then met to create one reconciled Arabic version. The backward translation of the reconciled Arabic version was done by a third student who was proficient in English.

The questionnaire was pilot-tested on a sample of 10 parents of autistic children and PSMMC-AC service users, five males and five females who lived in Riyadh. Pilot testing is helpful to assess the face validity and usefulness of the survey items (Langbecker et al., 2017). Pilot testing of the ITUQ revealed contradictions in three responses. Three respondents disagreed with the statement ‘When confidentiality is guaranteed, I would be happy to use video of me and my child as part of telemedicine.’ item 8. However, the same respondents responded with agree or neither agree nor disagree to items 12 and 13, which allow the researcher to store parent-child interaction videos. Thus, further reviewing of the questions was done by six therapists and one staff and parent of an autistic child. The feedback gathered was considered and resulted in a minor change in item 8 by adding the phrase 'with the therapist' to avoid ambiguity.

5.3.4 Data Analysis

The data were analysed descriptively, and inferential statistics were used to investigate differences between male and female respondents. Analyses were run using IBM SPSS Statistics (Version 27). The analyses included measurements of central tendency, i.e., means and standard deviations. Inferential statistics of nonparametric Mann-Whitney was used to determine the effect of gender on all ITUQ items.

5.3.5 Ethical Approvals

This study has been reviewed and granted ethical approval by the University of Reading Research Ethics Committee (Ethics no. 18/57), the Scientific Research Centre Ethics Committee at PSMMC (Ethics no. 1142).

5.4 Results

The results from the ITUQ related to the previous experience of using telemedicine showed that only 20% (n=9) of all respondents had heard about telemedicine. In addition, only 9% reported using telemedicine services before. As shown in Table 5.2, most of the respondents either agreed (n= 19) or strongly agreed (n=20) to use telemedicine when available (*M*= 4.07, *SD*=1.08). 79% of the respondents (n=37) either agreed or strongly agreed that using telemedicine in patient care is a good idea (*M*= 4.07, *SD*= 1.03). 74% of the respondents (n=35) believed they have the ability to use telemedicine (*M*= 4.02, *SD*= 1.01). Further, 76% of the respondents (n=35) either agreed or strongly agreed with the statement

Table 5.2. Intention to Use Questionnaire Results (using a 5-point Likert scale where 1 = strongly disagree and 5 = strongly agree).

Item		n	Overall *M*(SD)	Females *M*(SD)	Males *M*(SD)	U-value	p-value
3	Using telemedicine is a good idea.	47	4.07 (1.03)	4.17 (1.10)	3.86 (.86)	210	.361
4	I believe telemedicine could be beneficial.	47	4.05 (1.05)	4.14 (1.15)	3.86 (.77)	200.5	.255
5	I intend to use telemedicine.	47	4.07 (1.08)	4.07 (1.22)	4.07 (.73)	235.5	.762
6	I believe I have the ability to use telemedicine.	46	4.02 (1.01)	4 (1.13)	4.07 (.73)	233	.990
7	People who are important to me would approve of my using telemedicine.	46	3.93 (1.06)	3.97 (1.11)	3.86 (.95)	224.5	.704
8	I would be happy to use video of me and my child as part of telemedicine.	47	3.77 (1.04)	3.79 (1.08)	3.71 (.99)	255.5	.859
9	I would be interested in taking part in research involving telemedicine.	46	3.95 (1.09)	3.83 (1.19)	4.21 (.80)	290.5	.211
10	I would be happy to share a video with the research therapist.	46	3.72 (1.12)	3.66 (1.20)	3.86 (.95)	261	.480
11	I would be happy to share a video with the research therapist and a second researcher.	46	3.84 (1.11)	3.83 (1.20)	3.86 (.95)	238.5	.881
12	I will allow the research therapist to store the video for later viewing.	47	3.86 (1.01)	3.83 (1.07)	3.93 (.92)	242.5	.896
13	I will allow the research therapist to store video for later viewing with a second researcher.	47	3.86 (1.01)	3.83 (1.07)	3.93 (.92)	242.5	.896

‘People who are important to me would approve of my use of telemedicine’ (*M*= 3.93, *SD*=1.06).

Items 9-13 aimed to investigate participant’s acceptability to participate in future telemedicine trials and share videos of parent-child interaction. The results showed that 80% of respondents (n=37) either agreed or strongly agreed to consider taking part in future telemedicine trials (*M*= 3.95, *SD*= 1.09). Moreover, 74% (n=34) of the respondents either agree or strongly agree to share video with the researchers for coaching purposes (*M*= 3.84, *SD*= 1.11), and 70% (n=33) either agree or strongly agree to allow the researcher to store the video for later viewing with and without a second researcher (*M*= 3.86, *SD*= 1.01) for both items 12 and 13. However, more uncertainty and disagreement was observed for the same items (12, 13), with 17% of the respondents neither agree nor disagree and 4% strongly disagree to storing videos for later viewing. The results showed no significant difference between males and females across all ITUQ items (see Table 5.2).

5.5 Discussion

The aim of this first part of the pre-feasibility trial work was to investigate parents' views on acceptability and ITU telemedicine and participate in future telemedicine trials. The findings from the ITUQ revealed high acceptability toward using telemedicine for clinical and research purposes among PSMMC-AC clients. This finding supports previous findings suggesting the willingness of parents of autistic children to enrol in intervention involving parent coaching via telemedicine (Iacono et al., 2016; Salomone et al., 2017).

However, the respondents reported limited knowledge and experience of telemedicine. The results from the ITUQ showed that only 20% (n=9) of all respondents have heard about telemedicine, and 9% reported using telemedicine services before. Little or no experience in using telemedicine was reported by parents of autistic children in a community-based setting (Iacono et al., 2016). Although a small number of participants had heard about telemedicine at the time of this study (before the COVID-19 pandemic), the majority (n=39) reported intention to use this model of service delivery based on their understanding of the provided lay introduction about telemedicine. This result contrasted previous findings from the Midwestern state of the United States, suggesting that caregivers reported no intention to use telemedicine and prefer to receive EI services in-clinic (Yang et al., 2020).

Although the data showed high acceptability toward using telemedicine, 15% do not think that their close people will allow them to use it. Being allowed to use telemedicine by caregiver's close people scored the second-highest disagreement by the respondents following acceptability to share video with no significant gender differences. Little is known about the attitudes of female and male parents toward using telemedicine, i.e., whether females and males differ in their acceptability of telemedicine and, if yes, whether these differences will affect the decision of using it. This finding suggests further research is needed to understand family acceptability in different cultures when planning interventions using telemedicine.

There was some indication in the ITUQ findings of increased uncertainty and disagreement in items assessing parent's acceptability to share and allow storing of video-recorded parent-child interaction. The unacceptability of sharing video-recorded mother-child interaction was reported in a previous feasibility study in Riyadh (Alquraini et al., 2018). Although 44% of the participants reported acceptability to participate in research involving telemedicine and video-feedback strategy, it is worth noting the increase in the uncertainty and disagreement for the acceptability to storing video as it may affect the recruitment rate and compliance with aspects of the intervention involving video-feedback in future trials.

Overall, the findings from this study supported the decision to use videoconferencing and video-feedback strategy in the procedures of the feasibility study conducted in this context. However, several limitations were acknowledged. First, the sample is small and was gathered in a specific population, i.e., PSMMC-AC service users. Second, although the ITUQ was developed from the Technology Acceptance Model, a valid and reliable tool, the reliability and validity of the ITUQ have not been established. Finally, given that most of the respondents (80%) have not heard about telemedicine before, it is possible that their responses were affected by the lack of knowledge about this model of service delivery.

5.6 Introduction to the Practicality of the Telemedicine Platform

The second area of focus in this feasibility study is the practicality of the intervention. Bowen et al. (2009) described practicality as the feasibility of the program, method, or measures used with the targeted population at a specific context with consideration to the available resources. In this study, the EI program is likely to be practical since it was developed from the treatment-as-usual (TAU) demonstrated by the SLTs at PSMMC-AC (see Chapter 3 Section 3.5.2). However, it is necessary to establish the practicality of delivering this face-to-face TAU intervention via telemedicine. Therefore, the practicality of the telemedicine platform and procedures need to be tested.

Previous systematic reviews revealed various videoconferencing platforms were used in delivering interventions to parents of autistic children, such as Skype, GoToMeeting, Google Meet, and VSee (Akemoglu et al., 2019; Ferguson et al., 2019; Simacek et al., 2020). When choosing a telemedicine platform, researchers suggest considering the security, compliance, and platform features (Simacek et al., 2020). Health information such as patient's identifiable information, diagnoses, treatments, and medical test results must be securely protected to ensure the confidentiality of the services (HIPAA Journal, 2021). Several platforms have met the Health Insurance Portability and Accountability Act (HIPAA) 1996 requirement for the privacy and security of health information include Skype for Business, Zoom for Healthcare, Webex and VSee (HIPAA Journal, 2018, 2020).

Platform features play an important role in the success of the telemedicine sessions, especially when videoconferencing technology alone is not enough, e.g., when there is a need to share intervention materials with the parent. Moreover, providing performance feedback is an essential component in parent-mediated interventions (see Chapter 1 Section 1.5.3.1). The therapist may choose to provide feedback live during real-time parent-child interaction or on previously recorded materials (Snodgrass et al., 2017). In live feedback, it is essential to guide the parent on camera placement to allow adequate observation and support the coaching process (Snodgrass et al., 2017).

However, the therapist may choose to provide feedback using previously recorded video of parent-child interaction, i.e., video-feedback strategy (Snodgrass et al., 2017). In this case, the features of the telemedicine platform must be considered. Features such as sharing screen or sharing file allow the parent to watch and reflect on their own behaviour to enable informed feedback to be delivered remotely (Snodgrass et al., 2017). Moreover, in the video-feedback strategy, parents are guided to share the video with the therapist before the coaching session using an online secure transfer method (Snodgrass et al., 2017).

Researchers highlighted the need to investigate the challenges that could be faced when delivering interventions via telemedicine, e.g., difficulty with installing, launching, or using the telemedicine platform (Lerman et al., 2020). Two systematic reviews concluded that limited information had been published about the technology and telemedicine platforms used in previous intervention studies (Akemoglu et al., 2019; Ferguson et al., 2019). Selecting user-friendly software is important to achieve the goals of the intervention and minimise troubleshooting sessions (Lerman et al., 2020). Thus, this study aimed to assess the efficiency of the procedures and resources planned to be used in the upcoming feasibility study, i.e., videoconferencing platform and video-transfer feature.

5.6.1 Study Aim

- To test the practicality of delivering parent-mediated early intervention remotely via videoconferencing.

5.7 Method

5.7.1 Design

A short feasibility study design was planned to test the practicality of the platform. One of the key objectives of feasibility studies is the evaluation of the resources and ability to manage and carry out the study and the intervention (Orsmond & Cohn, 2015).

5.7.2 Participants

One Saudi mother, MT10, was recruited to help in testing the practicality of the telemedicine platform. The parent and her child met inclusion criteria to be used in the feasibility trial, which involve i) Arabic speaking parent having a ii) child age ≤ six years old, iii) diagnosed with ASD using the Autism Diagnostic Observation Schedule, 2nd Edition (ADOS-2) (Lord et al., 2012) and clinical judgments, iv) with or without co-occurring condition and, v) have access to the internet at home.

Parents of autistic children (aged < 6 years) who are clients of PSMMC-AC were approached to achieve the fourth aim. Parents were approached in two ways; those who have participated in previous research and gave permission to be contacted to participate in future research were contacted via phone by the researcher. A brief description of the study was given, and the information sheet was sent via WhatsApp. Another way was by approaching parents face-to-face during the regular follow-up visits at PSMMC-AC by the researcher. A brief description of the study was given along with the information sheet. In both ways, parents were asked to take the time and read the information sheet. They were asked to contact the researcher to express their interest in participating in the study either in-person at the centre or through the phone.

All approached parents were informed about their right to withdraw at any stage of the study. Ongoing recruitment of parents took around five weeks. A total of four parents were approached, two at the centre, two via phone. One parent agreed to participate and written informed consent was obtained from the participant at the clinic. The participant was 43 years old, a teacher with a bachelor's degree. She was living in Riyadh at the time of data collection. The child's medical file was accessed to confirm the diagnosis and to access the ADOS-2 score. The child was four years and five months old, diagnosed with autism, and had a total score of 24 in Module 1 of ADOS-2.

5.7.3 Telemedicine Platform

Webex Meetings platform was selected for testing before the feasibility study. The aim of this step was to check whether or not this platform was practical for coaching parents on the EI program. Webex was selected because it is HIPAA compliant, has AES 128-bit encryption with an end-to-end encryption option, and PIN-protected access into the meeting room (HIPAA Journal, 2018). Webex can be installed on any computer, smartphone, or tablet with an internet connection (Webex, 2021). Moreover, Webex offers sharing content and sharing screen features that allow the researcher to share previously recorded videos with the parent to provide feedback (Webex, 2021). In addition, Webex offers a file transfer feature that allows the participant to send the videos recorded at home to the researcher before the coaching session (Webex, 2021).

5.7.4 Data Collection

The participant was involved in a short trial of the EI program to test the practicality of the platform and the outcome measure. The participant was asked to install Webex on her preferred device. The full-scale EI program involves eight intervention sessions delivered in two months (one 60-min session/week). However, for the pre-feasibility testing, the participant was provided with four intervention sessions in one month. The four sessions were selected from the full program based on the child's social communication needs and parent's preference.

In each session, the participant received an email containing a link to allow her to join the meeting room. After each session, the participant was asked to spend around 30 minutes daily practising the EI strategies at home. The participant was instructed to video-record 5-min of her interaction with the child during natural daily activities for feedback and training purposes. Moreover, the researcher guided the participant on how to upload the weekly training videos to the platform through the Webex file transfer option using screenshots of the steps from the application.

The videos then were downloaded by the researcher to an external encrypted memory device to be transferred to the researcher'1s password-protected OneDrive space, where the videos were stored. The videos were named anonymously using an alphanumeric code and stored on the University of Reading cloud storage (student’s OneDrive) as recommended by the University of Reading Ethics Committee. The videos were destroyed from Webex and from the external memory right after being transferred. Participant’s personal details were stored in a password protected file separate from their anonymised data.

5.7.5 Ethical Approvals

This study has been reviewed and granted ethical approval by the University of Reading Research Ethics Committee (Ethics no. 18/57), the Scientific Research Centre Ethics Committee at PSMMC (Ethics no. 1142).

5.8 Telemedicine Platform Testing Outcomes

In this section, the challenges faced during the delivery of intervention sessions via Webex platform and potential solutions will be presented. During this short trial, three issues were faced, and they were all technical problems. The first one was detected when using the sharing content/file feature, which was not apparent before the trial. The platform did not support the .MOV file type during the time of this study. However, this technical issue was solved by converting the videos to .MP4 files before the coaching session.

The second issue was related to the ease of use of the URL sent automatically by the platform to the participant's email to join the meeting room. The participant reported complexity in opening and copying the URL from the email message received to the Webex application. This issue was resolved by using the meeting number instead of the URL. The meeting number was sent to the participant through the research number WhatsApp (a popular communication application in Saudi Arabia) before each session. By doing this, the participant needed to copy the meeting number from the WhatsApp conversation to the Webex application and was described to be simpler than opening the email message.

The third and most critical issue was faced when using Webex file transfer feature to receive the videos recorded by the participant. In order to use this feature, the researcher must start a live meeting with the participant, and both must remain online until the end of the transfer process. This required both the researcher and the participant to meet the day before the session because it cannot be done in an asynchronous manner. In addition, transferring a 5-min video with a very good resolution using home internet was a very slow process which took at least 20-minutes and required the use of a desktop.

Due to the challenges faced in using Webex file transfer feature, another external file transfer method was selected and tested. Moreover, a transient courier (SendThisFile) and not a data storage provider was selected for its ease of use and the customisable page (SendThisFile, 2019). SendThisFile is HIPAA configurable and was set up to align with HIPAA privacy and security requirements (SendThisFile, 2021). SendThisFile can be used directly by the participant from any device with an internet connection and does not require the researcher to be online during this process. In addition, it can be customised and supports the Arabic language, which made this process easier for the Arabic/non-English speaking parents.

5.9 Discussion

The study aimed to test the practicality of the telemedicine platform and video transfer method. Researchers highlighted the need to investigate the challenges that could be faced when delivering interventions specific to the selected telemedicine platform (Akemoglu et al., 2019; Lerman et al., 2020). The study enabled us to figure out whether Webex is suitable to achieve the feasibility aims in this context and with the targeted population. Overall, Webex was a practical platform to deliver EI and coach parents using videoconferencing and sharing content/screen features in Riyadh.

Two technical issues that had a direct impact on the ease of use of the telemedicine platform were faced during this trial. These technical issues are joining Webex meeting room and transferring weekly parent-child interaction videos. However, these pitfalls were treated successfully with the help of the participant to enhance the feasibility of the platform. Remaining in phone contact with the participant during the telemedicine sessions helped in resolving technical issues. Researchers recommended remaining in phone contact with caregivers during telemedicine sessions to ensure ample communication (Lerman et al., 2020).

The findings from this study informed the decision to use videoconferencing and video-feedback strategy in the procedures of the feasibility study conducted in this context. However, it is worth acknowledging that the technical issues and solutions used in this study applied to one participant, these technical issues and their solutions may not be the ones, or only ones, experienced by the larger sample recruited to evaluate the feasibility of the intervention.

5.10 Introduction to the Development of an Observational Outcome Measure

The need for an observational measure of parent-child interaction was recognised whilst designing the feasibility study. Several standardised assessment tools have been developed to measure social communication impairments in autistic children, e.g., Autism Diagnostic Observational Scale (ADOS) (Lord et al., 2000), Childhood Autism Rating Scale (CARS) (Schopler et al., 2010), Vineland Adaptive Behaviour Scales (VABS) (Sparrow et al., 2016), Social Responsiveness Scale (SRS) (Constantino & Gruber, 2012), Brief Observation of Social Communication Change (BOSCC) (Grzadzinski et al., 2016), the Dyadic Communication Measure for Autism (DCMA) (Aldred et al., 2004), and the Early Social Communication Scales (ESCS) (Mundy et al., 2003).

These assessments measure child’s social communication skills using self-completed surveys by child’s parent or teacher, e.g., SRS or can be administered by a trained professional, e.g., ADOS, VABS, and DCMA. The professional-administered measures may involve interviewing child’s caregiver, e.g., VABS, or by direct observation of child’s social communication and interaction, e.g., ADOS, BOSCC, and DCMA. Direct observation of child’s social communication behaviours includes both highly structured observational procedures, e.g., ADOS and ESCS, and less structured observations of child or parent-child interaction, e.g., DCMA and BOSCC.

Behavioural observation measures can be used to diagnose ASD and provide a rating of child’s characteristics, e.g., ADOS (Lord et al., 2000). ADOS is a diagnostic tool that measures the degree of impairment in child’s social communication and restricted and repetitive behaviours. Behavioural observation measures have also been used to measure changes in core ASD features, e.g., BOSCC (Grzadzinski et al., 2016), and child's social communication, e.g., DCMA (Aldred et al., 2004).

Behavioural observation measures are sensitive to change and can be conducted in natural contexts, which allow evaluation of spontaneity and generalisation (Cunningham, 2012). Thus, behavioural observations are recommended to be used in intervention studies of social communication as one measure combined with standardised measures of features severity and adaptive functioning (Cunningham, 2012; Grzadzinski et al., 2016; Green et al., 2010). Moreover, guidelines recommend that standardised tests should constitute only a part of the assessment of the communication profile of the autistic child as their skills may be situation-specific (le Couteur, 2003).

Observation of child's communication behaviours can be gathered by observing therapist-child or parent-child interaction during play. However, in parent-mediated interventions, the interventions might be particularly efficacious in improving parents' responsiveness and sensitivity to their child's communication bids (Green et al., 2010). Parental synchrony was found to mediate intervention outcomes for autistic children following parent-mediated intervention programs (Aldred et al., 2012; Green et al., 2010; Siller & Sigman, 2002). Researchers suggested that autistic children whose parents provided more learning opportunities had significantly higher cognitive and language scores (Davlantis et al., 2019). Thus, observation measures of parent-child interaction in naturalistic settings can provide an in-depth understanding of parent and child's responsiveness (Green et al., 2010; McConachie et al., 2015).

To date, few tools have been developed to measure video-recorded parent-child interaction in unstructured natural play (McConachie et al., 2015). Researchers pointed out the importance of developing sensitive and valid objective tools to measure the change in parent-child interaction (Grzadzinski et al., 2016; McConachie et al., 2015). A systematic review conducted by McConachie et al. (2015) suggested the Brief Observation of Social Communication Change (BOSCC) may potentially serve as a tool that is responsive to change in autistic children below six years. However, BOSCC was designed to measure the change in child's behaviours only with no focus on parent's communication behaviours and responsiveness (Grzadzinski et al., 2016).

Several parent-mediated intervention studies reported coding parent and child communication behaviours (Aldred et al., 2004; Guðmundsdóttir et al., 2019; Law et al., 2018; McDuffie et al., 2013; Siller & Sigman, 2002). One study reported the development of the Dyadic Communication Measure for Autism (DCMA), an established measure of parent-child dyadic interaction (Aldred et al., 2004). The DCMA measures child social communication behaviours as well parental synchrony and responsiveness. Multiple coding systems of parent and child behaviours have also been reported in previous intervention studies (Guðmundsdóttir et al., 2019; Law et al., 2018; McDuffie et al., 2013; Siller & Sigman, 2002).

However, these developed measures or coding systems of parent-child dyadic interaction lack published protocols (Aldred et al., 2004; Siller & Sigman, 2002), did not report psychometric properties (Guðmundsdóttir et al., 2019; Law et al., 2018; McDuffie et al., 2013; Siller & Sigman, 2002), and may require training (Aldred et al., 2004). These measures also have been tested on populations from the United Kingdom (Aldred et al., 2004), North America (McDuffie et al., 2013; Siller & Sigman, 2002), Southeast Asia (Law et al., 2018), and Europe (Guðmundsdóttir et al., 2019). Therefore, it is difficult to draw a conclusion about the suitability of using these behavioural observation measures to evaluate intervention outcomes in other populations.

According to Orsmond and Cohn (2015), evaluating data collection procedures and outcome measures is one of the main objectives of feasibility studies. Feasibility studies allow the evaluation of the appropriateness of data collection procedures and outcome measures for the targeted population (Orsmond and Cohn, 2015). Some of the questions that can be addressed in feasibility studies are ‘Do the measures appear to be performing in a consistent way with the intended population as compared to measurement information available in the literature?’ or ‘Does a suitable outcome measure need to be developed?’ (Orsmond and Cohn, 2015).

Often, researchers choose measures that have been used before with similar populations and interventions (Orsmond and Cohn, 2015). However, to choose a robust outcome measure, researchers suggested focusing on three factors i) the primary goal of the intervention, ii) the external validity of the measure, and iii) responsiveness to change (McConachie et al., 2015). The primary goal of the intervention planned in Part II of the feasibility study is to improve child’s social communication by enhancing parent’s synchronous communication. The DCMA was found to be the only measure developed for research purposes that meets the goal of the intervention and is sensitive to change (Aldred et al., 2004; Green et al., 2010). The DCMA measures the amount of mutually shared attention between the parent and child, parent synchrony and responsiveness, and child communicative initiations and responses (Aldred et al., 2004).

However, using DCMA as an outcome measure for the feasibility study and testing its feasibility on other populations, i.e., the Saudi population is not possible due to financial constraints. Therefore, this work aimed to develop a behavioural observation measure of parent-child interaction in an unstructured natural context. In addition, the intra- and inter-rater reliability for this measure will be established before testing it in the targeted sample of the main feasibility study.

5.10.1 Aims

- To develop a behavioural observation measure of parent-child interaction.
- To establish reliability for the developed parent-child interaction measure.

5.11 Method

5.11.1 Materials

The observational measure was developed and tested using four videos previously obtained from two parent-child dyads, clients of the Centre for Autism at the University of Reading. One four-year female diagnosed with Soto syndrome, and one five-year and three months male diagnosed with ASD. The parent-child dyads have been previously videoed individually during natural play (two videos for each dyad). The total duration of the four videos was 44 minutes.

5.11.2 Development of Parent-Child Interaction Measure (PCIM)

PCIM is a behavioural observation measure of parent-child interaction in an unstructured natural setting. PCIM was developed to be used as a primary outcome measure in the main feasibility study. PCIM consists of parent and child codes categorised in three domains: social communication domain (SCD), requesting domain (RD), and synchrony domain (SyncD). The parent and child’s codes used were adapted from Aldred et al. (2012), Mundy et al. (2003), and Pasco et al. (2008). Bottema-Beutel et al. (2014) definitions of social communication milestones were also used to guide the selection and the description of the codes. In addition, child’s codes of joint attention were developed from ADOS-2 (Lord et al., 2012) and definitions presented by Meindl & Cannella-Malone (2011) and Yoder &

McDuffie (2006). The development of PCIM was done in two phases. Both phases are described below.

5.11.2.1 Phase I. The first phase represents the development of the first batch of codes in the period from March to September 2019. At this initial phase, the PCIM consisted of 11 codes which were repeatedly tested using the videos and under the supervision of Dr Tom Loucas and Dr Fiona Knott (Table 5.3). The SCD included five child's codes i) initiation of joint attention, ii) responding to joint attention, iii) imitation, iv) social communication act, and v) maintaining social interaction and two parent/child codes vi) terminating social interaction and vii) dyadic interaction. The RD included two child's codes: initiated request and prompted request. The SyncD included two parent's codes: synchronous communication act and asynchronous communication act.

Table 5.3. Parent-Child Interaction Measure (PCIM) List of Codes.

		Code	Subject	Domain
1	IJA	Initiated joint attention	Child	Social communication
2	RJA	Responding to joint attention		
3	M	Imitation		
4	SCA	Social communication act		
5	MSI	Maintaining social interaction**		
6	DI	Dyadic interaction*	Parent/child	
7	TSI	Terminating social interaction		
8	IR	Initiated request	Child	Requesting
9	PR	Prompted request		
10	AsyncCA	Asynchronous communication act	Parent	Synchrony
11	SyncCA	Synchronous communication act		

*Code was discarded in phase I. **Code was discarded in phase II.

The dyadic interaction code was developed to code any parent's synchronous communication act followed by child's social-communication act or responding to joint attention. The code dyadic interaction was discarded because it did not define a single behaviour, and it can be measured later in the analysis using statistical methods (see Appendix 5 for codes' definitions in phase I and Table 5.4 for final codes). At this phase, all codes were designed as point events, i.e., point event behaviour is when the behaviour has no duration. Thus, coding behaviours as point events provide a frequency count for each behaviour.

5.11.2.2 Phase II. Phase II represents the refinement of the codes developed in phase I and establishing reliability between coders. This phase took around 17 months, from October 2019 to February 2021. At this phase, the PCIM consisted of 10 codes after discarding the dyadic interaction code from the SCD in phase I (see Table 5.3). Therefore, the SCD constituted of six codes (five child's codes and one parent-child code). One of the child's codes in the SCD was maintaining social interaction. The maintaining social interaction code was developed to measure child's ability to maintain social interaction, e.g., by taking turns with the parent, especially in children with very limited initiations. However, this code was discarded because it was negatively affecting the interrater reliability agreement scores as it was inaccurately coded as responding to joint attention.

The definitions of the final nine PCIM codes were refined at this phase after several practice sessions of around 150 hours with four MSc Psychology and MSc Language Sciences students. For example, the initiated joint attention (IJA) was defined as *‘spontaneous initiation of joint attention by shifting her/his eye gaze from an object to the parent, for the purpose of sharing a topic or focus with the parent either action, feelings/emotions, experiences, games, or objects. It involves a reference to the parent and the object by coordinated looking, showing, or giving.’*. The coding instructions for the IJA code initially involved some instructions like *‘Use this code if the child IJA using eye gaze accompanied with pointing for the purpose of showing’*. Additional instruction was added at this phase *‘Use this code if the child IJA using eye gaze accompanied with verbal behaviour, i.e., comment, naming objects, etc.’*

Another example is the social communication act (SCA) code which was initially defined as *'This code is used for any meaningful context-related communication act initiated by the child for the purpose of socialising.'*. The refinement of this code resulted in the following definition *'This code is used for any meaningful context-related communication act produced by the child for the purpose of socialising without coordinated looking.'* The first definition was limited to child's initiations and did not clarify whether the child was required to make eye contact with the parent or not. Because of this, the SCA code was confused with IJA code.

The definitions in the requesting domain also lacked details on whether the child's request behaviour differs when the child request with or without making eye contact at the same time. To keep the PCIM simple, the codes were not divided into levels or supported by modifiers, e.g., requesting with eye contact vs requesting without eye contact. Instead, the phrase 'with or without coordinated looking' was added to the initiated and prompted request codes, e.g., the initiated request code was redefined as *'This code is used for any communicative act initiated by the child, verbal or non-verbal or both where an object or action (e.g., to open a snack or to blow bubbles) is requested with or without coordinated looking. This code is also used when the child requests a game or activity, i.e., tickling.'*.

A minor change was also made to the coding instructions of the asynchronous communication code. Initially, the code was defined as *'This code is used for any asynchronous communicative act verbal or non-verbal used to direct or instruct the behaviour of the child or used to elicit a direct response from the child to a question, e.g., command or question.'* with no coding instructions. At this phase, two coding instructions were added *'This code is used if the parent delay in responding to the child.'* and *'This code is also used if the parent fails to respond to the child.'*.

In phase I, all child's and parent's codes were coded as point events. However, after exercising the codes, synchrony domain codes (parent's codes) were modified to state events instead of point events. Unlike point events, state events have a duration with start and endpoints. The SyncD codes were modified to state events to improve the reliability among raters which was initially difficult to achieve because when a parent was producing communication acts in a continuous manner, these were difficult to be broken down into similar segments of single behaviours or point events reliably by all raters. Coding parent's communication acts as state events also enhanced the practicality of PCIM by decreasing the time spent in coding the videos. Due to this change, the synchronous communication act and asynchronous communication act codes were renamed as synchronous communication and asynchronous communication because the codes cover an episode of communication (state event) rather than a single act.

5.11.3 Final Codes

The aim of this pre-feasibility work is to develop a behavioural observation measure of parent-child interaction. As shown in Table 5.4, the PCIM consists of nine parent and child codes categorised in three domains: social communication (SCD), requesting (RD), and synchrony (SyncD). The social communication domain includes four child’s codes i) initiation of joint attention, ii) responding to joint attention, iii) imitation and iv) social communication act, and one parent/child code terminating social interaction. The requesting domain includes two child's codes: initiated request and prompted request. The synchrony domain includes two parent's codes: synchronous communication and asynchronous communication. Each code is defined and supported with coding instructions (see Table 5.4 for codes' definitions).

Table 5.4. Definitions of Parent-Child Interaction Measure (PCIM) Codes.

Domain	Code	Subject	Definition
Social communication	Initiated joint attention	Child	Spontaneous initiation of joint attention by shifting her/his eye gaze from an object to the parent, for the purpose of sharing a topic or focus with the parent, either action, feelings/emotions, experiences, games, or objects. It involves a reference to the parent and the object by coordinated looking, showing, or giving. - Do NOT use this code if the child's initiation may have been elicited by parent's movement or verbalisation. - The child does NOT have to look back at the object. - Use this code if the child IJA using eye gaze accompanied with pointing for the purpose of showing. - Use this code if the child IJA using eye gaze accompanied with verbal behaviour, i.e., comment, naming object, ...etc.
	Responding to joint attention	Child	Response to joint attention elicited by the parent. The child must shift her/his eye gaze following parent's eye gaze or pointing gesture to an object for the purpose of responding to a topic or focus with the parent, e.g., parent says 'Look! and point toward something or by pointing/gesture only. It involves a reference to the object by coordinated looking, acknowledgement of parent's focus, showing, sharing, or giving. - The child must clearly follow the shift in parent's eye gaze, pointing, or gesture by immediately turning his/her head and eyes to the appropriate area where the object is located.
	Imitation	Child	This code is used for child's intent to imitate the parent using physical, gestural, vocal and speech behaviours with appropriate intonation. - This code of imitation must always be spontaneous (not physically prompted). - This code is used for the imitation of conventional and unconventional gestures. Conventional gestures are gestures with social meaning, e.g., nodding instead of "yes" or shaking head for "no". Unconventional gestures are gestures with no social meaning, e.g., drinking out of a toy cup. - Child's attempt to repeat parent's speech or vocalisations with identical intonation is considered echolalia and must NOT be scored using this code.
	Social communication act	Child	This code is used for any meaningful context-related communication act produced by the child for the purpose of socialising without coordinated looking. - Use this code for any communication act verbal or non-verbal, in which the child is communicating for the purpose of sharing, giving or showing, e.g., pointing for the purpose of sharing an event or pointing for the purpose of showing the parent an object without coordinated looking. - Use this code for any verbal communicative act, e.g., comments produced by the child for the purpose of spontaneously referring to an event, object, person, or action, without coordinated looking. - Do NOT use this code if the child produced verbal behaviour, e.g., comment or statement in response to parent's question or statement (elicited by parent).

			- Self-directed verbal communicative act must NOT be coded unless they are clearly part of social interaction with the parent.
	Terminating social interaction	Child/ Parent	This code is used when social interaction is terminated by the child or the parent. The child may end a social interaction by running away from the parent, shifting his attention to a new object or action, or by using avoidance behaviours, e.g., crying or lying on the floor. The parent may end a social interaction by talking to the therapist or answering a phone call.
Requesting	Initiated request	Child	This code is used for any communicative act initiated by the child, verbal, non-verbal, or both, where an object or action (e.g., to open a snack or to blow bubbles) is requested with or without coordinated looking. This code is also used when the child requests a game or activity, i.e., tickling.
	Prompted request	Child	This code is used for any child's communicative act, verbal, non-verbal, or both, prompted by the parent, where an object or action (e.g., to open a snack or to blow bubbles) is requested with or without coordinated looking. - Use this code when the parent prompts the child either verbally and/or non-verbally, including full or partial physical prompting and gestural prompting.
Synchrony	Asynchronous communication	Parent	This code is used for any synchronised face-to-face interaction aimed to support and facilitate the behaviour of the child for the purpose of initiating and maintaining the flow of the interaction and child's attention by acknowledging child's focus of interest and using timely reciprocal communication. - This code is used for any verbal communicative act produced by the parent, including comments, statements, and acknowledgement. - This code is also used for any non-verbal communicative act produced by the parent, including movements and facial expressions. - Use this code when parent imitates the child's either verbally or through movements and gestures. - This code is used ONLY when child is attending, or parent must wait until the child is refocused, pacing their actions to maximise the child's attention, i.e., pausing to give the child a chance to act.
	Synchronous communication	Parent	This code is used for any synchronised face-to-face interaction aimed to support and facilitate the behaviour of the child for the purpose of initiating and maintaining the flow of the interaction and child's attention by acknowledging child's focus of interest and using timely reciprocal communication. - This code is used for any verbal communicative act produced by the parent, including comments, statements, and acknowledgement. - This code is also used for any non-verbal communicative act produced by the parent, including movements and facial expressions. - Use this code when parent imitate the child's either verbally or through movements and gestures. - This code is used ONLY when child is attending, or parent must wait until the child is refocused, pacing their actions to maximise the child's attention, i.e., pausing to give the child a chance to act.

5.11.4 Coding Software

Behavioural Observation Research Interactive Software (BORIS) was used to practice PCIM codes and measure reliability. BORIS is free and open-source software that allowed a user-specific coding system to be set for a computer-based review of previously recorded or live videos (Friard & Gamba, 2016). BORIS also offered the choice of designing codes as point or state events and calculating Cohen's kappa coefficient for inter-reliability analysis between two observations.

5.12 Reliability

The PCIM reliability was established by the researcher and two MSc psychology students with no previous knowledge or experience in social communication measures. Intra-rater reliability was established in a 5-min video by both the researcher ($\kappa = .81$) and MSc student ($\kappa = .84$) with excellent agreement. Interrater reliability was established in a 5-min video by two raters independently with excellent kappa agreement ($\kappa = .80$). Moreover, the interrater reliability scores increased after discarding the MSI code. Before discarding the MSI code, two raters were able to establish interrater reliability independently with a moderate agreement ($\kappa = .60$).

5.13 Discussion

The need to develop a behavioural observation measure to count the frequency of parent synchrony, asynchrony and child's communication behaviours emerged during the planning stage of the feasibility study. Despite the efforts made in previous research, measuring parent-child interaction in unstructured natural context has not been widely addressed in the quantitative literature of autistic children under six years (McConachie et al., 2015). The development of the PCIM originates to meet the feasibility study need for this outcome measure and might help in filling this gap in the literature.

The PCIM was developed with the intention to capture the change in child's social communication behaviours and parental synchrony that may occur in relatively brief periods of time. Similar to BOSCC and DCMA, the PCIM is an evaluative tool and possibly a measure of change and not intended to provide any diagnostic classification (Aldred et al., 2004; Grzadzinski et al., 2016). The PCIM is an observational method of previously recorded videos and does not rely on caregiver reports allowing blinded coding and minimising bias. The PCIM scores at any single time point cannot stand alone and are only meaningful in relation to another time point.

The PCIM codes were selected based on their relevance to the behaviours being targeted in the intervention and do not code any irrelevant behaviours that are not directly targeted in the intervention. The inclusion of irrelevant test items that are not targeted in the intervention has been reported to influence the sensitivity of change measures (Vermeersch et al., 2000). Moreover, the analysis of the psychometric properties of the PCIM indicates that the PCIM has excellent interrater reliability, meeting recommended standards (Cunningham, 2012). The high interrater agreements suggest that this level of agreement is possible across experienced and inexperienced coders in the area of social communication batteries.

It is difficult to highlight the similarities and differences between the PCIM and the DCMA as the latter is unpublished and can only be accessed through full training (Aldred et al., 2004). However, as with any other measure in its early development, the PCIM has several limitations in light of the previously published measures. First, some psychometric properties of the PCIM, e.g., test-retest reliability and validity, need to be established to ensure the accuracy of the measure’s scores (Cunningham, 2012). Second, the PCIM captures behaviour's frequency only, unlike the BOSCC, which captures both the frequency and quality of the assessed behaviours (Grzadzinski et al., 2016). Researchers suggested that a limited range of response options may influence the measure's sensitivity to change (Vermeersch et al., 2000).

The PCIM is helpful in identifying changes in the behaviours targeted in the parent-mediated NDI of the feasibility study and does not capture the broader changes in social communication skills. Thus, the PCIM must be used with consideration to the behaviours targeted in an intervention. A similar limitation was reported for the BOSCC (Grzadzinski et al., 2016). The PCIM was also developed by coding the social communication behaviours of English-speaking autistic children under six years. Therefore, its suitability to code the behaviours of older autistic children or Arabic-speaking preschoolers with social communication impairments is not known. Moreover, our knowledge about the feasibility of using PCIM with Arabic preschoolers is limited and needs to be addressed in the feasibility study in order to meet its objectives.

5.14 Chapter Conclusions

This initial stage of the feasibility work aimed to investigate areas of acceptability and practicality in using telemedicine to deliver EI services in PSMMC. This work also aimed to develop and evaluate behavioural observation outcome measure to be used in the intervention stage of the feasibility study. The findings from the ITUQ brought insight into parent’s acceptability to use telemedicine and participate in telemedicine trials. The study findings showed that acceptability to parents’ of telemedicine as a mean of delivering an EI service is promising. The findings also reflected parents' willingness to participate in future telemedicine research trials. The ITUQ findings suggested that there was minimal knowledge of telemedicine among PSMMC-AC clients at the time of this study. It is worth highlighting that this study was conducted in 2019 before the emergence of the COVID-19 pandemic, which may enhance public awareness about telemedicine services.

The study led to solving technical problems to enhance the efficiency of the platform and improve participant experience before conducting the feasibility study. These preliminary findings revealed that using Webex platform is practical to deliver parent-mediated EI in a synchronous manner. Choosing a practical telemedicine platform is important to achieve the goals of the intervention and minimise the time wasted in troubleshooting technical and connectivity problems (Lerman et al., 2020). However, further testing of the usability and practicality of the telemedicine platform with a larger sample is important to support this recommendation.

The study aimed to develop and test the reliability of the behavioural observation measure PCIM to be used as a primary outcome measure in the feasibility study. The PCIM consists of nine parent and child codes measuring communicative bids during social interaction. The findings showed high interrater agreements among coders with or without experience in social communication measures. Moreover, the findings suggest that the PCIM is a useful and reliable tool to be used as a primary outcome to measure the change in pre-post parent-mediated intervention. However, further assessments of the PCIM test-retest reliability and validity are needed.

Introducing telemedicine as a way to deliver autism services will potentially increase the accessibility to autism professionals and services, especially to Saudi military families located far from specialised centres. In addition, telemedicine is expected to address disparities in accessing autism services by ensuring continuity of services. This piece of work is a step toward understanding the acceptability and practicality of using telemedicine by the Autism Centre service users at PSMMC. The findings from this feasibility research have informed the decision to use Webex videoconferencing, video-feedback strategy, and PCIM in the procedures of the intervention stage of the feasibility study conducted in this context.

However, the study did not investigate professionals' perceptions and attitudes toward using telemedicine with the autism population in this context. In light of the findings from previous research about the barriers of adopting telemedicine in the region (AlSamarraie et al., 2020) and in PSMMC (Alnasser, 2017), the findings must be treated with caution as it did not test the implementation and usability of telemedicine. In the next chapter, areas of implementation and usability of telemedicine will be addressed.

Chapter 6: Feasibility Study Part II

6.1 Introduction

Inadequate autism services in the Kingdom of Saudi Arabia was identified by previous research (Alnemary, Aldhalaan, et al., 2017; babatin et al., 2016). Researchers reported that lack of availability of ASD services is one of the barriers to timely access ASD services (Broder Fingert et al., 2019). Researchers warned that military families who have an autistic child face more challenges in accessing services (Cramm et al., 2019; Davis et al., 2016). Military families like those served at PSMMC-AC are likely to experience discontinuity of autism services due to the transitory nature of the military job (Cramm et al., 2019; Davis et al., 2016). Congruent with previous research, data from PSMMC-AC revealed that in the period from 2015 until 2018, 23% of the clients travelled from outside Riyadh to get autism services.

The results from the intention to use questionnaire (ITUQ) revealed that 82% (n=39) of the respondents intend to use telemedicine services when available at PSMMC-AC. These preliminary findings from the ITUQ support the need to introduce a novel service delivery model to deliver autism services remotely (see Chapter 5 Section 5.4). Telemedicine is a promising service delivery model to solve the inequity of accessing autism services among subpopulations, e.g., the military population.

The aim to evaluate the feasibility of telemedicine as a way to deliver early interventions for autistic preschool-aged children is well aligned with the plans of the KSA government. The Saudi Vision 2030 Health Sector Transformation Program aims to improve quality and efficiency and promote equity in healthcare services in the KSA (Vision 2030, n.d.). One of the key objectives of the Health Sector Transformation Program introduced by the Saudi government is to improve access to health services through comprehensive coverage and equitable geographical distribution. The Health Sector Transformation Program is committed to cover 88% of the Saudi population, including those in rural areas with health services by 2025.

One of the strategic plans of the Health Sector Transformation Program is expanding the provision of e-health services and digital solutions. In 2020, the Ministry of Health in the KSA successfully delivered over 8.6 million medical consultations remotely using a telehealth platform (Seha) and the call centre. According to the Communications and Information Technology Commission (CITC), 97.8% of the Saudi population aged 10-74 years have access to the internet (CITC, 2020a). The KSA ranked 7th worldwide in average mobile internet speed (CITC, 2020a). The average internet download speed in the KSA for fixed and mobile internet is 76-97 Mbps (CITC, 2020b).

The nature of telepractice demands the involvement of the parent in the EI program (Snodgrass et al., 2017). Remote delivery and parental involvement will allow the EI to be delivered in a natural environment, i.e., the child's home. Therefore, parent-mediated interventions (PMI) conducted in natural contexts are a viable approach to deliver EI via telepractice (see Chapter 2 Section 2.3). Further, PMI based on the developmental pragmatic approach are feasible to deliver EI via telepractice since these programs aim to promote child's interaction through parent's responsiveness and delivered in natural contexts.

6.1.1 The Rationale for Parent-mediated NDI

Promoting child's interaction through parent's responsiveness is a core theoretical assumption in the developmental pragmatic approach for autistic children (Ingersoll, 2010). This assumption is drawn from research indicating a relationship between caregiver's responsiveness and child's social-communication development (Aldred et al., 2004; Gulsrud et al., 2016; Pickles et al., 2016; Siller & Sigman, 2008). In the developmental pragmatic approach, caregivers are taught facilitative strategies to increase their responsiveness to child's communication bids (see Chapter 1 Section 1.3.2). Interventions based on this approach have shown promising outcomes and were particularly effective for supporting the acquisition of social communication skills (Sandbank et al., 2020).

Communication is considered social when it is 'inherently motivated by a desire to share with others' (Bottema-Beutel et al., 2014). Examples of deficits in social communication include failure to initiate and respond to adult's bids for joint attention, synchronise face-to-face interaction, comment on things or people in one's surroundings, and maintain another person's topic (Bottema-Beutel et al., 2014). The use of joint attention is a key aspect of social communication (Ingersoll & Dvortcsak, 2010). Ingersoll & Dvortcsak (2010) defined joint attention as 'the ability coordinate attention between an object and another person for social purposes; it includes showing, sharing, and pointing'. Joint attention is a particularly important skill because it provides a reference to learning language and social interaction (Ingersoll & Dvortcsak, 2010; Murza et al., 2016).

The deficit in nonverbal communication is a core symptom of the criteria of impairment in social interaction and communication in ASD as per the DSM-5 (APA, 2013). Nonverbal communication (gestures) serves an essential social function since they enable preverbal autistic children to communicate intentionally (Ellawadi & Weismer, 2014). For example, children use gestures to initiate joint attention by pointing to an object or event for the purpose of sharing experiences (Ellawadi & Weismer, 2014). Moreover, the development of these early gestures has been linked with the typical development of verbal communication (Bottema-Beutel et al., 2014).

Autistic children may lack interest or the ability to imitate others (Erickson Tomaino et al., 2014). Failure to imitate others interferes with the development of social communication skills learned through observation and imitation of others (Erickson Tomaino et al., 2014). Furthermore, early motor imitation skill was a predictor for later child's intentional communication (Sandbank et al., 2017). Thus, imitation is one of the primary targets for designing EI programs for autistic preschoolers (Sandbank et al., 2017).

Autistic children have been also found to engage in less play and develop play skills later than neurotypical children (Lam, 2014). The lack or delay of playing skills limits the autistic child ability to interact with peers because much of children's social interactions revolve around play (Erickson Tomaino et al., 2014). In sum, deficits in social communication and prerequisite skills like imitation and playing skills can affect long-term functioning and independence in autistic individuals (Erickson Tomaino et al., 2014). Thus, it is critical that EI programs effectively address these deficits to improve autistic children's ability to live and function independently (Erickson Tomaino et al., 2014).

The PMI differs from traditional therapist-delivered interventions not only in the agent of intervention but also in the extent to which intervention strategies are embedded within everyday activities and routines (Salisbury & Cushing, 2013). In the therapist-delivered interventions, the therapist focused more on the child rather than engaging and supporting the caregiver (Salisbury & Cushing, 2013). Researchers found significant differences between a triadic model of EI, i.e., PMI and therapist-delivered intervention (Salisbury & Cushing, 2013). Caregivers in the triadic intervention group showed significantly higher leadership and engagement than the therapist-delivered group (Salisbury & Cushing, 2013). However, researchers suggested two main variables that might mediate intervention outcomes within the triadic model: intervention fidelity and implementation fidelity (Neely et al., 2017). Since PMI is a triadic model of EI, the fidelity of implementation for the therapists and fidelity of intervention for the parents are equally important in ensuring positive outcomes for autistic children (Lieberman-Betz, 2015).

6.1.2 Measuring Fidelity within a Triadic Model

In intervention studies, the success of the implementation is investigated using fidelity measures (Neely et al., 2017). Previous research on PMI focused on fidelity measures such as implementation fidelity and intervention fidelity (Lieberman-Betz, 2015; Neely et al., 2017). Neely et al. (2017) defined implementation fidelity as the procedures used by the therapist to coach the parent in implementing the intervention (Neely et al., 2017). Further, intervention fidelity refers to the fidelity of procedures implemented by the interventionist, i.e., parent (Neely et al., 2017).

Multiple systematic reviews examined intervention fidelity outcomes in PMI (Fallon et al., 2020; Lieberman-Betz, 2015; Suess et al., 2013) and remotely delivered PMI (Neely et al., 2017; Unholz-Bowden et al., 2020). However, the literature on intervention fidelity outcomes for parents coached via telepractice is best described as limited due to the small number of studies, lack of methodological appraisal, and variability in fidelity measures (see Chapter 1 Section 1.5.3.1.2). Assessing intervention fidelity includes examining the quality of the strategies implemented by the parent, dose of strategy use with the child, parental engagement, and parent's implementation of intervention across different settings (Lieberman-Betz, 2015; Wainer & Ingersoll, 2013).

Researchers reported the use of various intervention fidelity measures such as parent self-report, direct observation of parent, or retrospectively using recorded audios or videos (Fallon et al., 2020; Wainer & Ingersoll, 2013). Fallon et al. (2020) found that autism practitioners tend to use direct observation measures of the parents compared to the indirect methods, e.g., parent self-report, in natural contexts. Researchers have developed direct observation tools to assess intervention fidelity in telemedicine delivered PMI, e.g., P-ESDM fidelity tool (Vismara et al., 2018) and parent skill assessment (Heitzman-Powell et al., 2014).

Vismara et al. (2018) assessed parent's intervention fidelity at baseline, post-intervention, and follow-up from two 5-min videos of parent-child interaction. Researchers reported evaluating parent's application of 13 intervention skills using 5 points rating scale, i.e., 1= no competence and 5=high competence. Some examples of the assessed skills are management of child's attention, quality of dyadic engagement, appropriateness of parent's language, and management of unwanted behaviours. According to Vismara et al. (2018), parents achieve fidelity when they score four or higher in each condition.

However, Heitzman-Powell et al. (2014) reported assessing a higher number of parent's skills during parent-child interaction. Researchers reported evaluating 41 parent's skills distributed in six activities pre- and post-intervention. The total time for the intervention fidelity assessment session was 40 to 60 min. Each skill was rated as either occurrence or non-occurrence and calculated in percentage points. The skill was rated as non-occurrence even when the parent showed an incorrect demonstration of the skill. Despite the progress in measuring fidelity, researchers highlighted the need for more research on measuring intervention fidelity in PMI (Fallon et al., 2020; Lieberman-Betz, 2015).

Researchers also highlighted a significant gap in reporting implementation fidelity exhibited by the therapists, which might moderate parental fidelity of intervention and subsequent child's outcomes (Lieberman-Betz, 2015; Neely et al., 2017). For example, Ingersoll et al. (2016) reported using a self-assessed fidelity checklist to assess coaching procedures at the end of each intervention session. However, researchers did not provide information about the content of the checklist.

Other researchers provided more details on the assessment method used for measuring implementation fidelity in parent-mediated NDI (McDuffie et al., 2013). McDuffie et al. (2013) reported the use of a 10-item checklist to evaluate the fidelity with which each clinician provided coaching and feedback. A trained observer rated the clinician's performance on a 5-point scale, with a score of five indicating that the clinician engaged in the described behaviour throughout the session and one indicating that the clinician failed to engage. The clinician was assessed on ten behaviours such as providing descriptive praise for successful strategy use, actively listening and problem-solving with the parent, and modelling language in response to child communication. In addition, McDuffie et al. (2013) reported rating clinician's performance in 25% out of 16 sessions. However, previous studies reported obtaining implementation fidelity scores from as low as 10% out of an average of 17 sessions (Heitzman-Powell et al., 2014) and 24 sessions (Ingersoll et al., 2016).

Although it is unclear how much fidelity is required to produce meaningful outcomes, a systematic review suggested the use of specific coaching components led to an increase in fidelity (Neely et al., 2017). Researchers reported that didactic verbal/written instructions and individualised performance feedback were linked to higher fidelity scores (Neely et al., 2017). Assessing fidelity within intervention research is critical for determining whether or not an intervention is effective and understanding how, why, and for whom a particular intervention works (Wainer & Ingersoll, 2013).

6.1.3 Implementation of the Telemedicine Model

The previously reported efforts of the government's entities in digital transformation led by the National Digital Transformation Unit highlights a rapid development to create digital infrastructure in the KSA (National Digital Transformation Unit, 2020). However, well-developed digital infrastructure alone is not an indicator of potential success in employing telemedicine as a service delivery model. Researchers suggested that cultural and social barriers, e.g., religious, social restrictions, and resistance to change, can possibly influence utilising telemedicine services in the region (AlSamarraie et al., 2020). The importance of considering cultural diversity in providing and adapting EIs was highlighted in previous research (Davenport et al., 2018; Lee et al., 2003).

Introducing telemedicine as a novel service delivery approach requires further research to investigate potential issues that could arise during remote coaching (Lerman et al., 2020). However, as described in Chapter 1, the research is limited not only in regard to remote coaching but also to PMIs delivered face-to-face in the Saudi context. Further, the recommendations related to the implementation of EI programs delivered remotely, e.g., parent involvement and natural context, were mostly developed from trials conducted in the West (Bottema-Beutel et al., 2014; Oono et al., 2013). Therefore, examining the application of the intervention program, i.e., parental engagement, the intensity of sessions and the duration in which the program can be completed in the Saudi context is essential.

6.1.4 Usability of the Telemedicine Model

Measuring the usability of telemedicine offers a way to evaluate the appropriateness of both the technology and the service (Parmanto et al., 2016). A common way to assess telemedicine usability is using usability questionnaires (Langbecker et al., 2017). Usability questionnaires were developed to measure patient usefulness, ease of use, technical quality, quality of interaction, and patient satisfaction (Langbecker et al., 2017; Parmanto et al., 2016). Examples of usability questionnaires: the Telemedicine Satisfaction Questionnaire (Yip et al., 2003), the Telehealth Usability Questionnaire (Parmanto et al., 2016), and the Technology Acceptance Model (Hu et al., 1999).

A study was conducted on 439 participants who received telemedicine services in Riyadh, KSA, during the COVID-19 pandemic suggested moderately high levels of satisfaction (68%) (Alharbi et al., 2021). Strikingly, nearly half of the participants reported that the quality of the tele-session would never be the same as the in-person session (Alharbi et al., 2021). In addition, Alharbi et al. (2021) reported a statistically significant gender difference in the level of satisfaction in favour of the male gender. However, it is unclear from the study why female participants were more neutral in their responses.

To our knowledge, the literature on telemedicine application in the KSA generally and usability of telemedicine is explicitly limited. Indeed, the research using reliable and validated Arabic measures of telemedicine usability is immature. For example, according to Alharbi et al. (2021), the questionnaire used in the study was originally developed in the United States and was translated from English to Arabic. However, the researchers did not report establishing reliability or validity for the tool that has been used. Therefore, it is clear that there is a need to develop or adopt telemedicine survey methods of usability to be used in effectiveness trials and patient experience studies conducted in Arab populations.

In sum, the effectiveness of parent-mediated EIs, remote coaching implementation, and telemedicine usability have not been well investigated in the Saudi context. The purpose of this study is to focus on how the parent-mediated NDI program can be successfully implemented using the telemedicine model of service delivery in the Saudi context. The study will investigate critical areas of feasibility as implementation and usability. In addition, the study will evaluate the efficiency of the resources developed or adapted for this context, e.g., intervention program and PCIM measure.

6.1.5 Part II Aims

- To test whether caregivers can be trained remotely via telemedicine.

- To investigate acceptability to caregivers of being coached via telemedicine.
- To test the usability of telemedicine in coaching caregivers.
- To assess the implementation of outcome measures.

6.2 Methodology

6.2.1 Study Design

The study was planned as a nonrandomised trial to test the feasibility of using telemedicine in delivering parent-mediated NDI for ASD in PSMMC-AC, Riyadh, KSA. However, due to COVID-19 pandemic lockdown and safety measures, the delivery of the intervention to the control group (in-clinic group) was interrupted. Because of the uncertainty associated with this global event, a pre-post feasibility study design with no control group was used. The feasibility design was used to investigate telemedicine's implementation, usability, and efficacy in the Saudi context. Exploring the real-world application of coaching parents on NDI targeting social communication via telemedicine is crucial prior to conducting a full effectiveness trial or introducing it as a service delivery model. Focusing on the implementation of the intervention is recommended and can be achieved using feasibility studies to understand to what extent a novel program can be successfully delivered to the targeted population in a structural but not fully controlled context (Bowen et al., 2009).

Studying the feasibility of telemedicine will provide evidence from a community-based setting of how telemedicine can be implemented with parents living in main cities and rural areas in the KSA. It will give an insight into parent's ability to engage remotely and take self-videorecording of parent-child interaction for feedback purposes (see Chapter 1 Section 1.5.3.1.2). It will offer further understanding of the minimal requirement of internet, i.e., fixed or mobile internet, speed of internet. In addition, studying the feasibility will bring an idea about the recruitment and attrition rates in this context (Tickle-Degnen, 2013). Finally, conducting a feasibility study will minimise the cost and efforts that might be wasted in future clinical trials (Tickle-Degnen, 2013).

6.2.2 Participants

6.2.2.1 Children Participants. Eleven parent-child dyads participated in the study. All children met the criteria for ASD by a multidisciplinary team based on DSM-5 criteria (APA, 2013). Children were assessed for eligibility using the Arabic version of the Social Communication Questionnaire (SCQ) (Aldosari et al., 2019; Allen et al., 2007) and Autism Diagnostic Observation Schedule (ADOS-2) (Lord et al., 2012). The SCQ is a parent-report questionnaire for assessing the risk of autism (Allen et al., 2007). ADOS-2 is a semi-structured, standardised assessment of communication, social interaction, play, and restricted and repetitive behaviours (Lord et al., 2012).

ASD diagnosis was confirmed for (n=6) using ADOS-2 before recruitment (Lord et al., 2012). (n=5) met cut-off (≥ 15) for being at-risk of ASD using the SCQ (Aldosari et al., 2019; Allen et al., 2007). One participant (NF23) was diagnosed with ASD and ADHD and was on medication for ADHD during the study. All children were males with mean age (*M*= 3:8) ranging between 2:3 to 5:6 years. Children were all nonverbal at recruitment except FS12 (participants' demographics are presented in Table 6.1). Vineland, a parent-interview measure, was used to evaluate children's adaptive functioning, including communication, socialisation, motor, and daily living skills (Sparrow et al., 2016). Vineland scores were retrieved from the participants' medical files to describe child's adaptive functioning (see Table 6.2 for children's characteristics).

Table 6.1. Participants' Demographics.

Participant	Parent age	Child age	Parent education	Parent job	Number of assistants at home	Other services received during the study	Other interventions received during the study	Child language level
ED13	39	4.9	Bachelor	Teacher	1	Autism centre	-	Nonverbal
FS12	50	4.9	Bachelor	Teacher	1	Inclusion	3 TAU sessions	Verbal
FT14	33	5	Masters	Dentist	1	Specific needs centre	-	Nonverbal
GA18	30	2.6	Diploma	Dental assistant	1	Autism centre	-	Nonverbal
JB20	30	3.2	High school	-	0	Specific needs centre	-	Nonverbal
NF23	39	4.3	High school	-	0	Autism centre	-	Non-verbal
RF26	36	2.4	Bachelor	Medical doctor	0	Nursery	2 TAU sessions	Nonverbal
TA16	39	3.8	High school	-	0	Specific needs centre	-	Nonverbal
WE17	36	2.4	Masters	-	2	-	-	Nonverbal
YR24	31	2.3	High school	-	0	Autism centre	4 TAU sessions	Nonverbal
YU22	42	5.6	Bachelor	Administrator	1	Autism centre	-	Nonverbal

6.2.2.2 Parents Participants. Participants were all female Arabic speaking, (n=10) Saudis and (n=1) Syrian. The mean age of parents was (*M*= 37), ranging between 30 to 50 years (Table 6.1). Participants' educational levels varied from high school (n=5) to master's degree (n=2). Two participants (ED13 and TA16) were living outside Riyadh in rural areas with a mean distance (*M*= 140) miles. Six of the participants were employed at the time of the study. Two participants (FS12 and TA16) were caring for other family members with specific needs along with the participated child at the time of the study.

Seven participants were recruited from Prince Mohammed bin Salman Program for Autism and Developmental Disorders (MBS-PADD): Autism Centre at Prince Sultan Medical City (PSMMC-AC), and four from the Child Development Centre at King Abdullah bin Abdulaziz University Hospital KAAUH in Riyadh, Saudi Arabia. The caregivers (clients of PSMMC-AC and KAAUH) were invited to participate in the study by texts messages sent by the researcher from the research contact number. The invite text was sent twice to the caregivers only if there was no response at the first time. The caregivers were asked to respond to the text if they are interested. The information sheet was sent via WhatsApp upon getting a response from the caregiver.

During their regular follow-up visits at the centres, the caregivers were also approached by research assistants (therapists). A brief description of the study was given to the caregivers along with the information sheet, and they were asked to take the time and read it. Then, they were asked to contact the researcher to express their interest in participating in the study on the research number provided. Finally, the research flyer was presented at the reception desk of PSMMC-AC and the Child Development Centre at KAAUH from September 2019 to February 2021. After that, however, the flyer was removed from the reception desks to comply with COVID-19 hygiene policies.

The recruitment process lasted 17 months, from September 2019 to January 2021. At least 121 caregivers were approached from both centres, with the majority (> 104 caregivers) recruited from PSMMC-AC. Out of the 121 invited caregivers, 14 (12%) agreed to participate, 14 (12%) responded with refusal, and 89 (74%) did not respond. Not all caregivers who refused to participate shared the reason. However, the reported reasons behind refusing to participate are 1) located outside Riyadh and not able to attend assessment sessions, 2) caregiver refused to be videoed, and 3) caregiver's spouse refused to share videos of mother-child interaction. All participants were informed about their right to withdraw at any stage of the study. The response rate was < 11% (14 out of at least 121). The attrition rate was 27%, with three out of 14 participants dropping out, resulting in 11 participants completing the study.

Table 6.2. Children's Characteristics.

	SCQ	ADOS-2			Vineland-II			
Participant	SCQ	Total score	Social affect	Restricted, repetitive behaviours	Communication	Socialisation	Daily living skills	Motor skills
ED13	-	23	17	6	30	25	42	40
FS12	-	13	11	2	33	43	37	34
FT14	-	24	18	6	13	13	18	25
GA18	-	13	12	1	64	78	87	88
JB20	20	-	-	-	61	65	73	79
NF23	28	-	-	-	52	59	66	67
RF26	18	-	-	-	76	91	102	114
TA16	-	16	12	4	-	-	-	-
WE17	25	-	-	-	-	-	-	-
YR24	28	-	-	-	59	70	80	85
YU22	21	22	18	4	40	40	66	-

SCQ Social Communication Questionnaire; ADOS-2 Autism Diagnostic Observation Schedule Second Edition; Vineland-II Vineland Adaptive Behaviour Scales Second Edition.

6.2.3 Intervention

6.2.3.1 Program Duration and Intensity. The intervention program is a parent-mediated EI program developed from a community-based setting, i.e., PSMMC-AC, for this study. The program consists of eight 60-min intervention sessions delivered over a period of eight weeks. Previously developed parent-mediated NDI has established evidence of efficacy by providing parents with 12 intervention sessions over six months period (Green et al., 2010). However, while there has only been limited work on the dosage of PMIs, currently, there is no evidence linking greater intervention intensity to enhanced outcomes (Nevill et al., 2016). As discussed in Chapter 4 p.101, the findings from parents' interviews informed the decision to examine the practicality of providing one intervention/parent-coaching session per week in this context.

6.2.3.2 Program Development. The program was developed by the researcher under the supervision of Dr Loucas and Dr Knott and was guided by the framework of Snodgrass et al. (2017), which intended to guide the conversion of in-person speech language therapy services to parent coaching programs that can be used in telepractice. The program is parent-mediated EI based on the principles of the developmental approach (see Chapter 1 Section 1.3.2) that uses video-feedback method to achieve parent and child targets. As shown in Table 6.3, the program has two main components: targeted skill and targeted strategy. The targeted skill refers to the child's developmental skill that has been targeted in the intervention. The targeted strategy refers to the evidence-based strategies and instructional techniques used to teach the parent how to produce the desired effect on the child. The parent's process of learning EI strategies is supported with reflection on their performance using the video-feedback method. In addition, the program contains supplementary examples of activities that have been designed for each goal.

6.2.3.3 Targeted Skills. The program focuses on improving child's social communication skills by changing parent-child interactions in naturalistic settings. One child's skill is targeted in each session, with a total of eight targeted skills for the whole program. These skills are joint attention, dyadic interaction, play skills, turn-taking, imitation, nonverbal communication (learned in two sessions), and verbal communication. Seven out of 8 of these targeted skills were selected from the unified intervention plan developed by the PSMMC-AC speech therapy team through participatory action research (for further details, see Chapter 3 Section 3.5.2). The targeted skills have been selected and synthesised against evidence-based programs of EI: Hanen More Than Words (HMTW), Paediatric Autism Communication Therapy (PACT), and Early Start Denver Model (ESDM) (Green et al., 2010; Rogers & Dawson, 2010; Sussman, 2012). The skills were chosen based on common elements

Table 6.3. Example of Targeted Skills and Strategies.

Child's Skill	Parent's Strategies	Supplementary Examples of Naturalistic Activities
Joint Attention	1. Adjusting the environment by minimising distractions. 2. Identifying what the child is attentive to. 3. Trying to be close on the same level, and face to face with the child during play. 4. Following child's lead. 5. Imitating child's sounds, gestures, facial expressions, actions, and words. 6. Pause and wait.	1. Play with the child in the same way he plays (opening and closing drawers or spinning wheels of the cars). 2. Blowing a balloon up gradually, pausing and waiting between each breath with exaggerated facial expressions during blowing.

approach i.e., the skills that were commonly targeted in previously mentioned programs were selected. Finally, the skills were targeted following the developmental trajectory of social communication (see Chapter 1 Section 1.3.2).

6.2.3.4 Targeted Strategies. Each session was designed to teach the parent EI strategies and techniques to achieve the targeted skill. These strategies were developed from four parent-mediated programs of EI: HMTW, PACT, ESDM, and imPACT (Green et al., 2010; Ingersoll & Dvortcsak, 2010; Rogers & Dawson, 2010; Sussman, 2012). As shown in Table 6.3, the parent is taught strategies to follow the child's lead during play, achieve balanced turns in interactions, adjust the environment to support the child's attention and engagement, and create lots of practice opportunities.

6.2.3.5 Video-feedback Method. The program involves a video-feedback method to allow the parent to identify and reflect on episodes of parent-child reciprocal interaction with the therapist. The video-feedback method has been used in parent-mediated NDIs like HMTW and PACT (Green et al., 2010; Sussman, 2012). The feedback was delivered following Ingersoll & Dvortcsak (2019) guidelines on providing positive and corrective feedback when coaching parents of autistic preschoolers on social communication skills. Providing feedback on previously recorded videos was selected over giving live feedback on parent's performance because of reported challenges associated with remote viewing (Lerman et al., 2020). See Chapter 1 Section 1.5.3.1.1 for further discussion on providing performance feedback in PMIs.

6.2.3.6 Supplementary Examples of Naturalistic Activities. Each goal in the intervention program was aided with examples of its implementation during playing, meal-time, dressing time, and other daily activities. For example, to teach dyadic interaction, the parent might be instructed to play peekaboo with a shirt or pants during dressing time. Some of the activities were developed by the speech therapists at PSMMC-AC, and others were selected or adapted from the following books and manuals: *An Early Start for Your Child with Autism: Using Everyday Activities to Help Kids Connect, Communicate, and Learn* (Rogers, Dawson, & Vismara, 2012), *More Than Words: A Parent's Guide to Building Interaction and Language Skills for Children with Autism Spectrum Disorder or Social Communication Difficulties* (Sussman, 2012), Motivate to Communicate: 300 Games and Activities for Your Child with Autism (Griffin & Sandler, 2009), *Early Start Denver Model for Young Children with Autism: Promoting Language, Learning, and Engagement* (Rogers & Dawson, 2010), *Teaching Social Communication to Children with Autism: A Practitioner Guide to Parent Training* and *Teaching Social Communication to Children with Autism: A Manual for Parents* (Ingersoll & Dvortcsak, 2010).

6.2.4 Procedures

The participants were coached remotely by the researcher and two certified speech therapists working at PSMMC-AC. Five participants received their coaching sessions by the researcher and six by the speech therapists. The coaching sessions were delivered between September 2019 to May 2021. The procedures were severely affected by COVID-19 lockdowns. The planned and compensatory procedures are explained in the following sections.

6.2.4.1 Introductory Session. An introductory meeting which lasted between 30-60 min was organised with all participants. The meeting was held in one of the speech therapy rooms at PSMMC-AC for participants recruited before the COVID-19 pandemic. For participants recruited during the pandemic, the meeting was gathered using Webex. The participants were contacted and received instructions on how to download Webex and join the meeting using WhatsApp. Webex is HIPAA compliant, has AES 128-bit encryption with an end-to-end encryption option and a locked meeting feature (HIPAA Journal, 2018; Webex, 2021). In this meeting, Webex platform and its sharing screen feature were introduced and tested with the participant (WebEx, 2021). In addition, the therapist explained 1) the nature and goals of the intervention program, 2) the implementation of the video-feedback method, 3) the video-transfer method used to send the training videos to the therapist the day before the session, and 4) encouraged the participant to ask questions to ensure that the procedures are clear.

6.2.4.2 Intervention Delivery. All participants completed eight remote-coaching sessions gathered using Webex in a minimum of 9 weeks and a maximum of 27 weeks (*M* = 18). The session's length varied between 18-84 min (*M* = 51). The time/date of the session was arranged with all the participants via WhatsApp. Before each session, the participant was provided with the meeting number via WhatsApp. In case of technical problems, the therapist connected with the participant either via WhatsApp or phone call depends on the participant's preference.

Following each session, the participant was asked to spend 30-min daily practising the strategies with the child at home. The participant was instructed to record a 5-min video or short clips (5-min in total) of her interaction with the child during natural activities the day before the following coaching session to allow the therapist to review and prepare informative feedback. Therefore, a total of eight videos, a video following each coaching session, was requested from the participant. At the end of the coaching sessions, participants were asked to complete the Telehealth Usability Questionnaire (TUQ) and participant demographics form after finishing the intervention program. The one-page demographics form was set to be completed after the intervention because it included details about the time spent in child's training and other interventions received during the study (if any). Participant demographics form is provided in Appendix 7.

6.2.5 Outcome Measures

6.2.5.1 Parent-Child Interaction Measure (PCIM). Child's social communication skills and parental synchrony were measured using PCIM; a direct behavioural observation measure was used to code a 10-min video of parent-child dyadic interaction pre- and post-intervention. The PCIM consists of both child and parent codes. The child codes include initiation of joint attention (IJA), responding to joint attention (RJA), imitation (M), and social communication act (SCA) grouped together in a social communication domain (SCD), and initiated request (IR), and prompted request (PR) grouped together in a requesting domain (RD). There are two parent codes synchronous communication (Sync) and asynchronous communication (Async). In addition, there was one parent/child code: terminating social interaction (TSI). The measure was developed for this study (further details on PCIM development and reliability is provided in Chapter 5 Sections 5.11.2 and 5.12).

Each parent-child dyad was given a 30-min appointment to play. They were video-recorded for 10-min during unstructured play with a standard set of toys available. A large plastic box with a small selection of toys was prepared. The box contained a doll with a pillow and blanket, a plastic cutlery set, two plastic cups, two plastic plates, two small cars, two small balls, and a toy phone. Before starting the video, the participant was familiarised with the available toys and was instructed to play with the child as they do naturally in their daily routines, with or without the set of toys. The recording started at the moment when the caregiver places all or some of the toys on the table/floor.

The pre- and post-intervention videos were collected between September 2019 and May 2021 by the researcher and assisting therapist in PSMMC-AC and KAAUH. PCIM was planned to be conducted in the clinics to provide a consistent context. However, due to COVID-19 lockdowns, the researcher guided six out of 11 participants to self-record the pre-, post-, or both videos at home. The videos collected in the clinics were recorded in a regular speech therapy clinic using a Samsung Camera placed on a portable tripod at the corner of the room, which was repositioned when needed. The therapy room has a small table, two small chairs, free floor space, with one inaccessible window and mirrored glass for observation purposes. A 30-min appointment was arranged for PCIM assessment pre- and post-intervention. The videos collected at participants' homes were recorded using their smartphones. The participants were instructed to share a photo from a clear angle of a place with minimal distractions at their homes to check suitability before recording the video. Participants were asked to prepare similar items at home to allow a consistent environment. A photo of the toys used for in-clinic video recordings was shared with the participants.

Pre-post videos were coded using Behavioural Observation Research Interactive Software (BORIS) (Friard & Gamba, 2016). BORIS, a free and open-source software, offers a user-specific coding system to be set for previously recorded videos. In BORIS, a project file was created containing all information related to the coding, including the codes, code description, category (domain), subject type (child or parent), and behaviour type (state or point event). The coding was done using a keyboard key set for each code, e.g., M for imitation. BORIS also allowed calculating Cohen's kappa coefficient for inter-reliability analysis by selecting two observations and a time window, e.g., a specific code must be present within the same one or two seconds in both observations. Interrater reliability was calculated for 27% of the observations. The mean agreement between two coders was (κ= .62) with a range of κ= .53 to κ= .68.

6.2.5.2 Fidelity of Implementation. Therapists' fidelity of implementation was assessed using a 9-item tool adapted from McDuffie et al. (2013). The tool uses a 5-Likert scale to evaluate the therapist's behaviour, with five scores given when the therapist engages in described behaviour throughout the session, and one score is given when the therapist failed to engage in described behaviour. As shown in Table 6.4, the tool examines various therapist's behaviours like active listening, engagement with the parent, and providing praise for successful strategy use. Implementation fidelity assessment was carried out live by two raters (speech therapists not involved in the intervention) using a 9-item tool adapted from McDuffie et al. (2013).

Due to COVID-19 lockdowns, the assessment was severely affected because live coding was impossible, i.e., most intervention sessions took place at the interventionists' homes. Furthermore, rating recorded coaching sessions was not possible because ethical approval was not obtained for recording sessions in addition to cultural barriers associated with video-recording and storing the sessions. Thus, implementation fidelity was obtained from one randomly selected coaching session for each therapist. The two speech therapists delivering the intervention were blinded to the qualities they were evaluated on, i.e., not familiar with the used tool. However, it was not possible to blind the researcher from the implementation fidelity items. The reliability between two coders for the three interventionists was 78%, 89%, and 100% (*M*= 89%).

Table 6.4. Implementation Fidelity Tool.

Items	Score Definitions
1. Engage in conversations and information sharing with parent.	5= The clinician engaged in described behaviour throughout the session.
2. Provide descriptive praise for successful strategy use.	4= The clinician engaged in described behaviour most of the time.
3. Encourage parent to implement all the strategies targeted in the selected session.	3= The clinician engaged in described behaviour some of the time.
4. Encourage parent to comment on successful/ unsuccessful strategy use.	2= The clinician engaged in described behaviour rarely throughout the session.
5. Model strategy use with accompanying explanation.	1= The clinician failed to engage in described behaviour throughout the session.
6. Encourage parent to reflect on strategy use and elicit individualised examples of activities.	
7. Model language/vocalisations describing child's focus of attention.	
8. Model verbal or non-verbal behaviour in response to child's communication acts.	
9. Actively listens and problem solves with parent.	

6.2.5.3 Intervention Fidelity. Intervention fidelity was measured for each participant by the assigned therapist from the observation of the weekly 5-min video-recorded parent-child interaction. Parent's application of taught strategies was coded as either fully achieved, partially achieved, or not achieved. This method was adapted from Heitzman-Powell et al. (2014). The parent's performance of every strategy was rated as fully achieved if the strategy was implemented accurately and used every time it was appropriate to do so, partially achieved if the strategy was not implemented completely accurately or was implemented accurately but not all the time, and not achieved when the parent fails to fully or partially achieve the strategy.

Parent's intervention fidelity was coded in two ways: frequency and scale ratings. In the frequency rating, the intervention fidelity was expressed as a percentage of fully achieved and partially achieved strategies of the total number of opportunities for applying the strategies. For example, when coding the strategy' sitting face-to-face and on the same level of the child', every time the parent was able to sit in a face-to-face position and on the same level will be coded as fully achieved. The strategy will be coded as partially achieved every time the parent was able to sit in a face-to-face position only or sit on the same level only but not facing the child. The total number of opportunities for applying the strategy equals the sum of the number of the fully achieved strategies, partially achieved strategies, and missed opportunities in which the parent could have applied the strategy but failed.

In the scale rating, parent's application of each strategy was given a score from zero to two. A score of two indicates that the strategy was fully achieved, a score of one indicates that the strategy was partially achieved, or the parent missed some opportunities, and a score of zero indicates that the parent fails to achieve the strategy both fully and partially. For example, in Table 6.3, one of the targeted strategies is adjusting the environment. This strategy will be rated as two (fully achieved) when the parent successfully adjusts the environment with no distractions in at least one setting throughout the video. The strategy would be rated as one (partially achieved) if the parent was able to adjust the environment in only one setting when multiple settings are observed in the video and/or was able to minimise some but not all distractions. Further, the strategy will be rated as zero (not achieved) when the parent fails to fully and partially achieve the strategy. If the strategy cannot be rated, e.g., not practised in the video, no rating will be given, and the data will be considered missing. Interrater reliability was calculated for 12.5% (one video for each parent) of the observations. The mean agreement between two coders was $\kappa = .68$.

6.2.5.4 Telehealth Usability Questionnaire (TUQ). The TUQ is a 21-item tool that was developed to evaluate the usability of using multi-purpose platforms, e.g., VSee, and Webex (Parmanto et al., 2016). The TUQ was selected because, in addition to measuring the satisfaction of using the telemedicine platform, it measures the usefulness, ease of use, reliability, and intention to use telemedicine. For example, the participants are asked to respond to statements like "telehealth improves my access to healthcare services" and "using the telehealth system, I can see the clinician as well as if we met in person" using a 7-point Likert scale (see Appendix 8).

Translation of the TUQ was permitted by the first author. A forward-backwards translation method was used following the Mapi approach (Acquadro et al., 2004). The translation was done by three undergraduate students, members of the Speech and Hearing Student Club at King Saud University. Two students worked individually on the forward translation and created two Arabic versions of the TUQ. The two students then met to develop one reconciled Arabic version (Appendix 9). The backward translation of the reconciled Arabic version was done by a third student who was proficient in English. Then, the researcher reviewed the backwards translation against the original version of the TUQ for finalisation.

The TUQ was collected by the researcher and assisting therapist post-intervention. A paper copy of the TUQ was completed by the participants assessed in the clinic (n=5). For participants who recorded their post-intervention video at homes (n=6), a soft copy of the TUQ was sent to them via their method of preference, i.e., WhatsApp or email.

6.2.6 Data Handling and Analysis Plan

The participants sent their videos to the researcher using SendThisFile, a transfer platform with an automatic deletion feature. SendThisFile is HIPAA configurable and was set up to align with HIPAA privacy and security practices (SendThisFile, 2021). The videos then were downloaded to an external encrypted memory device to be transferred to the researcher's password-protected OneDrive space, where the videos were stored. The videos were stored on the University of Reading cloud storage (student's OneDrive) as recommended by the University of Reading Ethics Committee. The videos were deleted from SendThisFile and the external memory after being transferred to the secured cloud storage.

Moreover, the process of coding PCIM videos using BORIS software required downloading the videos to the researcher's computer. Therefore, the videos were stored temporarily (less than three hours) in a password-protected file on a secured computer and were destroyed after coding. All PCIM and coaching videos have been named anonymously using alphanumeric codes. A password-protected Excel sheet was used to keep the participants' details separate from their anonymised data. Strict confidentiality was followed by storing the hard copies of the informed consent, TUQ and participant's information sheet in a locked cupboard. In case of obtaining the participant's consent, TUQ, and information sheet online, the soft copies of these forms were stored immediately in the researcher's OneDrive.

The data were analysed using descriptive statistics and estimation following Lee et al. (2014) approach on statistical interpretation of pilot trials. The PCIM and TUQ scores were analysed descriptively across participants with remote intervention as the independent variable with two levels: pre- and post-intervention. The analysis of PCIM scores included effect size and estimation measurements using 75, 80, 85, 90, and 95% confidence intervals assuming the minimum clinically significant difference > 0. In addition, mean calculations were done for coaching time, i.e., length of coaching sessions and videos used for feedback. The intervention fidelity data were also analysed descriptively within participants with strategy implementation as the independent variable with two levels 1) full achievement of strategy and 2) partial achievement of the strategy.

6.2.7 Ethical Approvals

This study was reviewed and granted ethical approval by the University of Reading Research Ethics Committee (Ethics no. 19/31), the Scientific Research Centre Ethics Committee at PSMMC (Ethics no. 1223), and the King Abdullah bin Abdulaziz Hospital Academic and Training Affairs (Ethics no. RO2019-O-006).

6.3 Results

6.3.1 Child Outcome Measures

Social communication domain (SCD) scores increased from *M*= 20.3 (*SD*= 19.4) pre-intervention to *M*= 23.2 (*SD*= 24.1) post-intervention. This small increase reflected a small effect size (r= 0.3). Per-domain mean scores for child's requesting behaviours decreased from *M*= 2.7 (*SD*= 2.9) pre-intervention to *M*= 2.6 (*SD*= 3.2) post-intervention. This small decrease reflected a small negative effect size (r= -0.11). Within child's domains, small effect sizes were observed only in the IJA, SCA, and PR codes (per-code mean scores and effect sizes are provided in Table 6.5).

Table 6.5. Parent-Child Interaction Measure (PCIM) Results for Children.

		Pre	Post	Difference (95% CI)	p-value	Effect size (r)
Domain	Code	*M* (SD)	*M* (SD)			
Social communication domain	IJA	12.8 (17.5)	14.9 (21.5)	2.1	.384	.26
	RJA	1.4 (1.8)	1.4 (2.3)	0	.916	-.03
	M	3.6 (5.7)	3.5 (3.7)	-0.1	.877	-.05
	SCA	2.5 (3.2)	3.5 (6.2)	1	.606	.16
	Total SCD score	20.3 (19.4)	23.2 (24.1)	2.9 (-1.3, -7.5)	.327	.30
Requesting domain	IR	0.6 (1)	0.3 (0.6)	-0.3	.336	-.29
	PR	2.1 (2.9)	2.4 (3.3)	0.3	.720	.11
	Total RD score	2.7 (2.9)	2.6 (3.2)	-0.1 (-2, 1.6)	.720	-.11

IJA initiated joint attention; RJA responding to joint attention; M imitation; SCA social communication act; IR initiated request; PR prompted request; *M* mean; SD standard deviation; CI confidence interval.

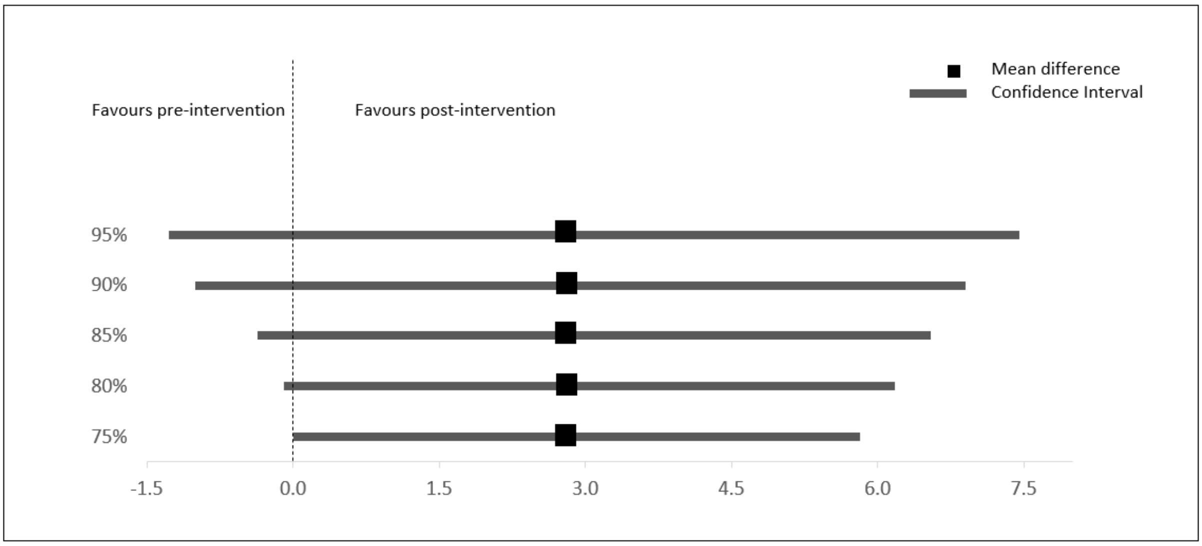

Figure 6.1. Mean Difference in Social Communication Domain Scores Between Pre-intervention and Post-intervention with Confidence Intervals.

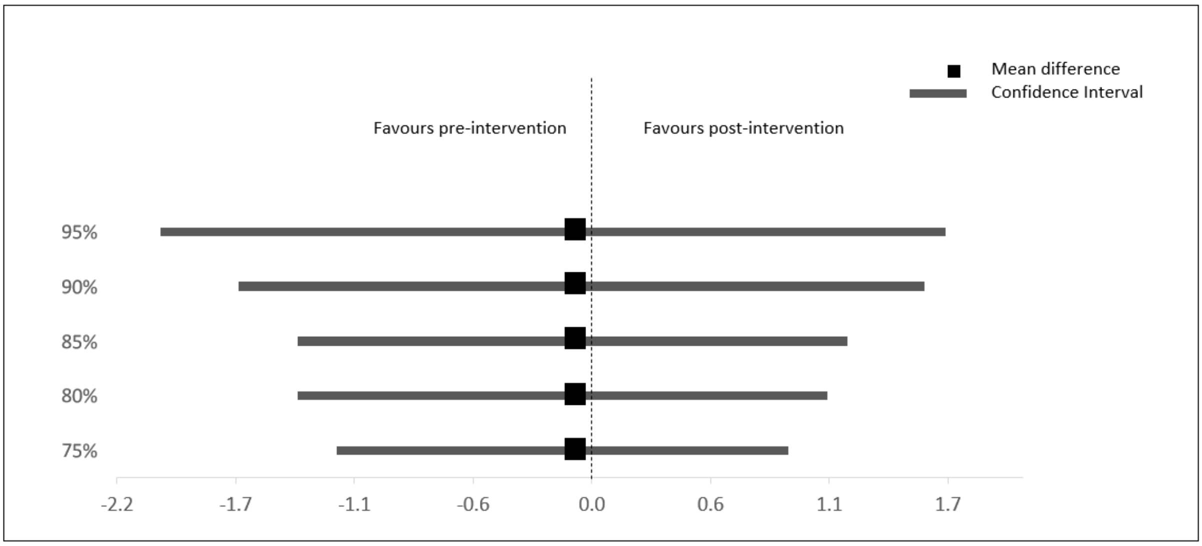

Figure 6.2. Mean Difference in Requesting Domain Scores Between Pre-intervention and Post-intervention with Confidence Intervals.

Figure 6.1 shows a range of confidence intervals for the mean difference in the SCD scores between pre- and post-intervention. Confidence intervals (CI) of 95%, 90%, 85%, and 80% crosses 0, these levels suggest a lack of evidence of a treatment difference. However, at a wide confidence interval of 75% there is just evidence difference in the SCD post-intervention. Figure 6.2 shows a range of confidence intervals for the mean difference in the

RD scores between pre- and post-intervention. None of the CIs is above 0, and these levels suggest there is no evidence of a treatment difference.

6.3.2 Parent Outcome Measures

6.3.2.1 Parent-Child Interaction Measure (PCIM). Parent's synchronous communication scores increased from *M*= 28.9 (*SD*= 19.4) pre-intervention to *M*= 35.9 (*SD*= 17.5) post-intervention and decreased for asynchronous communication from *M*= 60.7 (*SD*= 23.1) to *M*= 55 (*SD*= 20). As shown in Table 6.6, these small differences reflected small effect sizes for synchronous and asynchronous communication (r= 0.4 and -0.3, respectively).

Figure 6.3 shows a range of confidence intervals for the mean difference in the synchronous communication scores between pre- and post-intervention. Confidence intervals (CI) of 95% and 90% crosses 0, these levels suggest inconclusive evidence of a treatment difference. However, a confidence interval of 85% and smaller would be considerably above 0, suggesting at this level that there is a difference in parents' synchronous communication post-intervention. Figure 6.4 shows a range of confidence intervals for the mean difference in the asynchronous communication scores between pre- and post-intervention. None of the CIs is above 0, and these levels suggest there is no evidence of a treatment difference on parents' asynchronous communication even with a wide confidence interval.

Table 6.6. Parent-Child Interaction Measure (PCIM) Results for Parents.

	Pre	Post	Difference (95% CI)	p-value	Effect size (r)
Code	*M* (SD)	*M* (SD)			
Synch	28.9 (19.4)	35.9 (17.5)	7 (-2.5, 15)	.153	.4
Asynch	60.7 (23.1)	55 (20)	-5.7 (-15.7, 5.9)	.328	-.3

Synch synchronous communication; Asynch asynchronous communication; *M* mean; SD standard deviation; CI confidence interval.

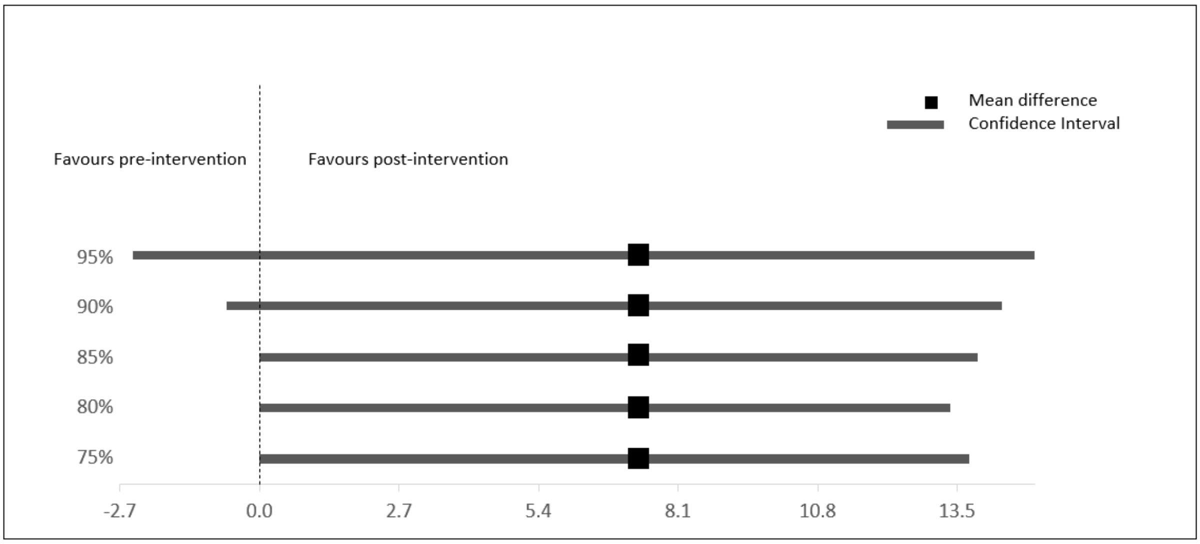

Figure 6.3. Mean Difference in Synchronous Communication Scores Between Pre-intervention and Post-intervention with Confidence Intervals.

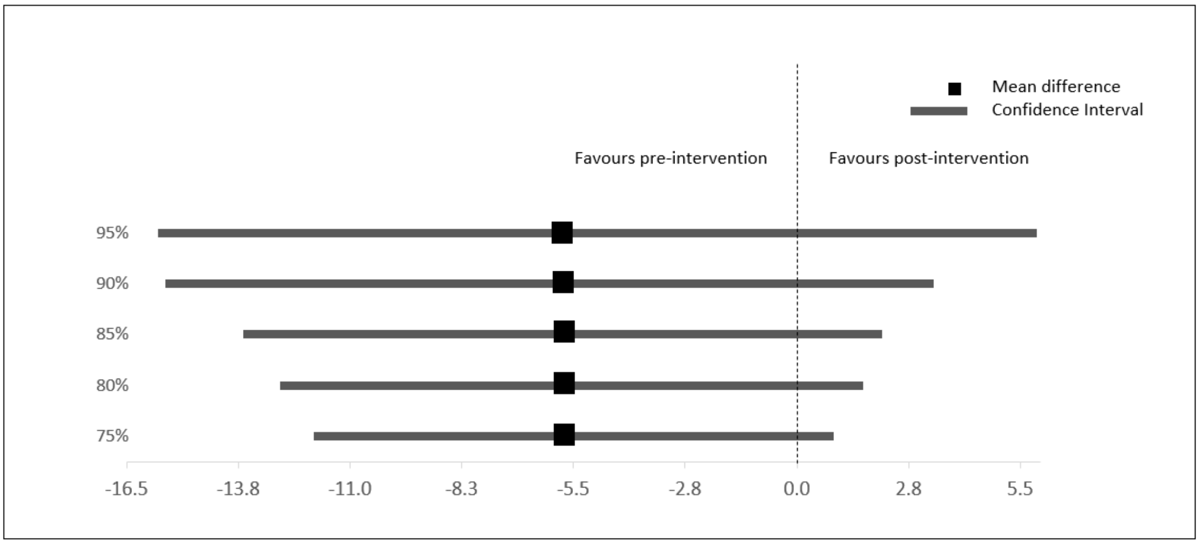

Figure 6.4. Mean Difference in Asynchronous Communication Scores Between Pre-intervention and Post-intervention with Confidence Intervals.

6.3.2.2 Intervention Fidelity. Parent's intervention fidelity was measured by observing the weekly video-recorded parent-child interaction, which was shared for feedback purposes. Thus, the results in this section reflect parents' intervention fidelity after receiving training only and prior to receiving performance feedback. The intervention fidelity was coded using frequency and scale ratings. The results of the scale rating are presented in this section (see Appendix 10 for frequency rating results). As shown in Table 6.7, none of the participants

Table 6.7. Intervention Fidelity, Program Duration, and Coaching Time Data for Each Participant.

		Intervention Fidelity		*Program Duration and Coaching Time*		
Participant	Total scored strategies (out of 42)	% of fully achieved strategies	% of fully or partially achieved strategies	Intervention program duration (weeks)	Average length of coaching session (min)	Average length of video used for feedback (mm:ss)
ED13	39	49	100	9	61	08:31
FS12	37	24	84	10	55	05:03
FT14	39	38	82	18	49	05:51
GA18	37	35	86	12	33	04:11
JB20	38	47	89	27	33	05:28
NF23	40	53	83	18	34	04:10
RF26	39	23	74	15	34	05:34
TA16	37	14	86	10	47	05:05
WE17	38	29	95	16	55	05:37
YR24	38	66	95	13	40	02:59
YU22	38	53	89	22	36	04:51

was assessed in all the 42 taught strategies due to missing data. Thus, the intervention fidelity scores were calculated based on the number of strategies assessed for each participant. Overall, participants achieved between 14-66% fidelity, with six of the eleven participants achieving fidelity between 38-66% for full achievement of all strategies. Higher fidelity scores were observed for the partial achievement of strategies, with all participants achieving 74% or more partial fidelity.

6.3.3 Program Duration and Coaching Time

As shown in Table 6.7, the duration of the intervention program (8 coaching sessions) varied widely between participants ranging from 9 to 27 weeks (*M*= 15). Three participants were able to complete the intervention in 10 or fewer weeks. The remaining eight required 12 or more weeks to complete the intervention. The total coaching time also varied between participants ranging from 296-549 minutes (*M*= 389) with an average length (*M*= 43.3) for the coaching session. Video-feedback data met or exceeded the weekly target (5-min) for 64% of the participants (n=7). Four participants did not provide the weekly targeted 5-min videos (*M*= 4) with a range of 02:59 to 04:51 min.

6.3.4 Telehealth Usability Questionnaire

The TUQ results revealed high levels of satisfaction post-intervention. As shown in Table 6.8, all participants reported they were satisfied overall (i.e., rated four or higher) with the experience of using telemedicine (Item 21: *M*= 6.6, *SD*= 0.8). All participants reported feeling comfortable communicating with the therapist (Item 18: *M*= 6.9, *SD*= 0.3) and were able to express themselves effectively using telemedicine (Item 13: *M*= 6.8, *SD*= 0.4). 91% of the participants loved using telemedicine (Item 8: *M*= 5.8, *SD*= 1.8) and thought telemedicine was an acceptable way to receive healthcare services (Item 19: *M*= 6.4, *SD*= 1). Intention to use telemedicine services in the future was also reported by 82% of the participants (Item 20: *M*= 6.3, *SD*= 1.8).

The findings showed that telemedicine was easily learned and used by all participants (Item 5: *M*= 6.5, *SD*= 0.9), (Item 6: *M*= 6.4, *SD*= 0.9), and (Item 9: *M*= 6.8, *SD*= 0.4). All participants reported being able to easily talk and hear the therapist using telemedicine with (Item 11: *M*= 7, *SD*= 0) and (Item 12: *M*= 6.6, *SD*= 0.8), respectively. All the participants reported being able to troubleshoot technical problems (Item 16: *M*= 6.1, *SD*= 0.9). However, less agreement was observed in believing the ability of the telemedicine platform to do everything the participant want it to be able to do (Item 10: *M*= 5.9, *SD*= 1.4).

All participants agreed that using telemedicine, they can see the therapist as if they have met in person (Item 14: *M*= 6.8, *SD*= 0.4). All participants agreed that telemedicine saves time spent in travelling to the clinic (Item 2: *M*= 6.7, *SD*= 0.6), and 82% agreed that telemedicine improved their access to healthcare services (Item 1: *M*= 6, *SD*= 1.3).

Table 6.8. Telehealth Usability Questionnaire (TUQ) Results. Agree = score of 4 or higher, Disagree = score of 3 or lower.

TUQ Item	*M* (SD)	% Agree (n)	% Disagree (n)
1. Telemedicine improves my access to healthcare services.	6 (1.3)	82 (9)	0
2. Telemedicine saves me time spent traveling to a hospital or specialised clinic.	6.7 (.6)	100 (11)	0
3. Telemedicine provides me the healthcare I need.	5.6 (1.4)	73 (8)	0
4. It was simple to use this system.	6.3 (1.3)	82 (9)	0
5. It was easy to learn to use the system.	6.5 (.9)	91 (10)	0
6. I believe I can be productive quickly using this system.	6.4 (.9)	91 (10)	0
7. The way I interact with this system is pleasant.	6.7 (.6)	100 (11)	0
8. I like using the system.	5.8 (1.8)	91 (10)	9 (1)
9. The system is simple and easy to understand.	6.8 (.4)	100 (11)	0
10. The system is capable to do everything I want it to do.	5.9 (1.4)	82 (9)	9 (1)
11. I can easily talk to a health practitioner using the telemedicine system.	7 (0)	100 (11)	0
12. I can hear the health practitioner clearly using the telemedicine system.	6.6 (.8)	100 (11)	0
13. I felt I was able to express myself effectively.	6.8 (.4)	100 (11)	0
14. Using the telemedicine system, I can see the health practitioner as if we met in person.	6.8 (.4)	100 (11)	0
15. I believe the visits made through the telemedicine system are equivalent to in-person visits.	5 (2.1)	55 (6)	18 (2)
16. Whenever I made a mistake using the system, I could modify errors easily and quickly.	6.1 (.9)	100 (11)	0
17. The system gave error messages that clearly told me how to fix problems.	5.9 (1.2)	82 (9)	0
18. I feel comfortable communicating with the health practitioner using the telemedicine system.	6.9 (.3)	100 (11)	0
19. Telemedicine is an acceptable way to receive healthcare services.	6.4 (1)	91 (10)	0
20. I would use the telemedicine services again.	6.3 (1.8)	82 (9)	0
21. Overall, I am satisfied with the telemedicine system.	6.6 (.8)	100 (11)	0

In addition, 73% of participants agreed that telemedicine could provide them with the healthcare they need (Item 3: *M*= 5.6, *SD*= 1.4). Further, the least agreement observed in the TUQ was for item 15, with only 55% (*M*= 5, *SD*= 2.1) agreed with the statement "I think the visits provided over the telehealth system are the same as in-person visits".

6.3.5 Correlations

Correlation analysis was done to explore the relationships between all study variables. As shown in Table 6.9, there were no significant correlations between variables. There was no significant correlation between parent's fidelity of intervention and all other variables. However, a strong positive relationship was found between parent's intervention fidelity scores and child's SCD scores (Spearman's Rho = 0.58). A strong positive relationship was also found between child's SCD scores and program duration (Spearman's Rho = 0.59) and between session length and TUQ scores (Spearman's Rho = 0.55).

Table 6.9. Nonparametric Spearman's Rho Correlation Coefficient Values.

	RD	Synch	Asynch	Program Duration	Video Length	Session Length	IF	TUQ
SCD	-0.37	0.2	-0.18	0.59	-0.01	-0.01	0.58	-0.06
RD		0.42	-0.42	0.21	0.39	-0.15	-0.22	-0.24
Synch				-0.13	0.32	0.09	0.18	0.17
Asynch				0.2	-0.33	-0.13	-0.12	-0.17
Program Duration					-0.10	-0.52	0.37	-0.17
Video Length						0.51	-0.39	0.06
Session Length							-0.14	0.55
IF								0.43

** Correlation is significant at 0.01 level (two-tailed).
SCD Social Communication Domain; RD Requesting Domain; Synch Synchronous Communication; Asynch Asynchronous Communication; IF Intervention Fidelity; TUQ Telehealth Usability Questionnaire.

6.3.6 Clinical Observations

During the intervention, notes were kept on the sessions, including the parents' challenges with the intervention protocol and telehealth. These feelings regarding the post-intervention assessment and reasons for requiring additional weeks to finish the program. One mother was worried that her child might not do better at post-intervention. She expressed that he was not at his best after the assessment and sent a video of child's interaction at home later in the day of the assessment to prove that his performance is better. One mother was postponing the post-intervention video for three weeks because the child was not engaged, and when he was engaged, she lacked assistance to record the video. She was also provided with the same instruction pre- and post-intervention. However, for the post-intervention video, the provided material showed the child interacting with his sister and was less than 10 min. Thus, the mother was asked to repeat it. Another participant was postponing the post-intervention video for ten weeks because she or the child was sick. She apologised because she delayed recording the video and expressed worry about forgetting the strategies because it has been a while. One mother preferred to attend the coaching session with her husband, and therefore, her children were not occupied by another family member. Because of this, she frequently struggled to devote her attention to the feedback. Three mothers frequently reported postponing the coaching sessions because they did not want to share a video in which the child did not achieve the targeted goal. One participant frequently reported postponing the coaching sessions because of other personal responsibilities and family obligations, e.g., travel and professional courses. Finally, one participant found the TUQ difficult to understand and asked the researcher for assistance in explaining the TUQ items.

6.3.7 Technical Observations

A minimum of 6 MBps bandwidth for download on each side and 11 MBps bandwidth for upload on the therapist's side is required for best videoconferencing experience using Webex in the study context. Technical issues were faced in 17% of the sessions provided to all participants, i.e., 99 telemedicine sessions. However, the total time wasted on technical issues was 1.8% (79 min) of the total coaching time provided to all participants (4285 min).

6.4 Discussion

The study investigated the feasibility of using telemedicine to deliver parent-mediated naturalistic developmental early intervention program (NDI) in the Saudi context. The study focused on the implementation and usability of the intervention. The study also evaluated the efficiency of the resources used, i.e., intervention program and outcome measures.

6.4.1 Implementation

The study aimed to evaluate the efficiency of the intervention program, outcome measures, and telemedicine platform. Overall, the results from this study support the feasibility of coaching parents of autistic children via telemedicine as evidenced by achieving partial fidelity of 74% or more of intervention strategies by all participants. Fundamentally, the results of the intervention fidelity achieved by parents were obtained from videos of parent-child interaction shared weekly after receiving the intervention instructions to get feedback on their performance. Thus, higher fidelity scores are anticipated after providing parents with performance feedback. Further, parental fidelity was measured from videos collected for the purpose of coaching to avoid overloading the parents by sharing more videos.

On the same matter, the data showed that almost all parents failed to engage in weekly coaching sessions and share a video for feedback every week. Although investigating parents' experiences is beyond the scope of this study, the clinical observations revealed that child's performance, parent's responsibilities, and other family obligations affected parent's engagement in the intervention. It is worth highlighting that parents hesitate to share a video to get feedback when they are not satisfied with their child's performance. Previous research reported that parents of autistic children found performance feedback using video-feedback method challenging (Leadbitter et al., 2020). Further, researchers suggested that reliance on a parent-mediated approach in telemedicine may require a high level of commitment with the potential of additional stress (Simacek et al., 2020). Possible solutions like decreasing the intensity of the program and sharing videos for selected sessions may improve parent experience.

One of the objectives of this study is to evaluate the reliability and practicality of the outcome measures. Due to COVID-19 lockdowns, the PCIM scores were obtained from self-recorded videos at participants' homes for over half of the sample. Although observing the child interacting in his everyday environment is likely to reflect real behaviours, careful collection of observational measures is vital. Self-recorded videos showed a decrease in visibility and inconsistency in the materials used compared to in-clinic recorded videos. In addition, the time required to send the post-intervention video to the researcher was 5.8 weeks on average compared to 1.2 for the in-clinic recorded videos. Thus, the study showed that relying on participants to record videos at home for the observational outcome measure, the PCIM, was not feasible.

Moreover, collecting videos of parent-child interaction for the outcome measure by the participants was not a feasible way of collecting reliable data. Previous telemedicine studies which reported collecting reliable data of parent-child interaction at home have been performed by researchers live either via videoconferencing (Meadan et al., 2016; Vismara et al., 2013) or by attending at participants' homes (Ingersoll et al., 2016). In this study, it was not possible to visit participants' homes during the COVID-19 pandemic. However, this finding emphasised the importance of collecting observational measures by the researchers either in-person or remotely to guide parents on visibility.

The study also showed that the implementation of the intervention fidelity measure using frequency coding was not a feasible approach. Coding how frequently parents performed intervention strategies was time-consuming and is possibly not reliable to evaluate strategies with high occurrence or difficult to segment, e.g., adding sound effect. Wainer and

Ingersoll (2013) observed that measuring fidelity of intervention using coding systems that evaluate the presence or absence of a particular strategy can be time-consuming and requires training and ongoing support to the coders. In contrast, the use of a rating scale in measuring intervention fidelity in parent-mediated NDI delivered via telemedicine showed high reliability between coders (Ingersoll et al., 2016). Congruent with previous findings, using a rating scale to assess parent's intervention fidelity showed substantial reliability among coders.

The study aimed to evaluate the efficiency of the telemedicine platform in coaching parents of autistic children. Overall, the intervention was successfully implemented using videoconferencing technology of the Webex platform as the time wasted due to technical issues was 1.8% of the total coaching time provided to all participants. Most of the faced technical issues were connectivity-related issues and were not related to the usability of the platform. Webex bandwidth requirement for one-to-one videoconferencing with content sharing is advised to be no less than 2 MBps for download and upload on each side (Cisco, 2021). However, the study findings suggest at least 6 MBps bandwidth for download on each side and 11 MBps bandwidth for upload on the therapist's side for the best experience.

The technical issues were solved without the need for a technician's help as most of them were related to connectivity issues. Staying in contact with caregivers helped in immediate troubleshoot of the technical problems. This finding supports researchers' recommendation of remaining in phone contact with caregivers to ensure adequate communication despite the technical problems that may arise during sessions (Lerman et al., 2020). This finding also supports previous reports suggesting that connectivity-related issues may reduce the efficiency of telemedicine but are not a barrier to effective telemedicine service (Lerman et al., 2020).

Finally, although Webex does not support the Arabic language, no issues were faced in running and using the application by the participants. This finding may favour providing participants with an introductory session to familiarise them with the telemedicine platform. Providing caregivers with an initial introductory troubleshooting session was suggested by previous studies (Lerman et al., 2020).

6.4.2 Usability

High levels of telemedicine usability and satisfaction were reported following the intervention. The results revealed that all participants were satisfied after being coached remotely and found the telemedicine platform easy to use. This finding is congruent with previous reports of high levels of satisfaction (Bearss et al., 2017; Vismara et al., 2018), and usability (Wainer & Ingersoll, 2015) following remotely delivered NDI. This finding is also congruent with previous research reporting 68% of respondents had a good experience after receiving telemedicine services in Riyadh (Alharbi et al., 2021).

However, the findings from the TUQ showed that only 55% thought telemedicine resembled in-person visits. This finding is in line with previous reports suggesting that 45% of respondents think that the quality of telemedicine services in community-settings in Riyadh would never be the same as in-person visits (Alharbi et al., 2021). Similar observations were reported by researchers who used TUQ to investigate patients' satisfaction and usability following telemedicine sessions utilising videoconferencing in the United States (Layfield et al., 2020). Although respondents were highly satisfied following telemedicine, researchers reported that the lowest average score was for the item asking whether telemedicine visits are equivalent to in-person visits (Layfield et al., 2020). Researchers have recommended that parent-mediated telemedicine interventions should be viewed not to replace but to improve and augment in-person interventions (Ferguson et al., 2019; Simacek et al., 2020), which is implied by the findings here.

6.4.3 Efficiency of Resources

Although the study did not aim to investigate the effectiveness of using telemedicine, it provided preliminary evidence for the usefulness of using telemedicine to coach parents of autistic children in the Saudi context. Findings from the intervention fidelity measure showed that parents could achieve fidelity at least for partially achieving the strategies. Over half of the participants achieved between 38% to 66% fidelity for full implementation of the strategies. These findings are consistent with previous studies indicating parents can achieve moderate to high fidelity when coached via telemedicine (Vismara et al., 2018; Wainer & Ingersoll, 2015).

The analysis of effect sizes of key variables child's social communication and parental synchrony showed small effect sizes across the entire sample, suggesting there is evidence of a nonsignificant treatment difference. Although the outcome measure used in this study (PCIM) was developed with the intention to capture changes in child's social communication and parental synchrony that may occur in relatively brief periods of time, it has not yet been tested for this purpose.

6.4.4 Limitations

Three major limitations were acknowledged. First, the study has a small sample size, a very low recruitment rate (< 11%), and moderate attrition rate (27%) which might be due to COVID-19 lockdowns or hesitancy of caregivers to being videoed. Second, low engagement was observed for most participants. The dosage for intervention sessions was M=47min less than the planned 60min and was delivered over 9-27 weeks. Also, some parents were selective about which video to share with the therapist. Possible bias in selecting videos with best child's performance for video-feedback may possibly affect the findings and must be carefully addressed when designing future parent-mediated intervention trials.

The study did not investigate the experiences of participants for being coached on parent-mediated intervention via telemedicine. Investigating parents' perceptions and experiences of using telemedicine is an important step toward understanding the factors that might have affected their engagement and performance during the intervention i.e., whether it is related to the pandemic, parent-mediated approach, or telemedicine. Therefore, future research should consider conducting qualitative studies on parents' experiences following remotely delivered parent-mediated intervention in this context.

Third, the PCIM was not fully developed due to time constraints, i.e., it was not tested on an adequate number of videos of autistic preschoolers. Thus, some pitfalls of the PCIM were noticed while coding the pre- and post-intervention videos. It was noticed that the imitation and initiated joint attention codes could overlap in time, i.e., occur at the same time. The social communication domain did not include social smile as a code, and thus, social smile was only coded when it combined joint attention behaviour. Finally, the materials used to facilitate parent-child interaction during assessment had triggered repetitive behaviours in some cases (n=2), which interfered with the social interaction. Thus, it is advisable to consider this possibility of using assessment materials in a repetitive manner and adjust the materials before stating video-recording.

COVID-19 lockdowns have negatively impacted the conduct of this study. First, the delivery of the intervention to the in-clinic group (control) was interrupted. Due to this severe interruption, changes were set on study design by abandoning the control group. Having a control group would have helped in testing participants' acceptability to being randomised, which will provide a ground for conducting future randomised trials in this population.

Second, live assessment of therapists' implementation fidelity at the clinic was interrupted. Third, missing scores or recent scores of the diagnostic measures for some participants hindered our understanding of the characteristics of the sample. Finally, the collection of the main outcome measure PCIM was done in an inconsistent setting, i.e., homes and clinics. In some cases, the self-recording of PCIM videos at homes led to decreased visibility, use of different materials, and delays in recording the post-intervention video. Therefore, these results provide an understanding of the resources and barriers in this context but not a certainty in outcomes.

6.4.5 Conclusions

The study represents a starting point to assessing telepractice as a delivery model for autism interventions in the Saudi context. Telemedicine may be an effective supplement to in-person parent-mediated interventions, particularly in big countries where rural geographic areas have limited services. Telemedicine may potentially help families with demanding work schedules or unpredictable lifestyles who cannot commit to attending frequent intervention visits, e.g., military families. Demonstrating the feasibility of delivering NDIs via telemedicine in this context is a small but important step toward the implementation of an evidence-based intervention in underserved rural areas. A more controlled pilot study is recommended to carefully evaluate intervention outcomes before conducting a large-scale trial.

Chapter 7: Conclusions

The current research is the first to investigate the feasibility of using telemedicine to deliver parent-mediated early intervention (EI) for autism in the Saudi context and has implications for offering this type of intervention in a non-Western context. The research also looked at how a community-based service can be adapted to meet the needs of underserved and mobile populations, i.e., people living in rural areas and military families. Further, the work is a starting point toward understanding how to adopt telemedicine as a novel service delivery model into an existing speech therapy clinic in Riyadh. The research provided evidence for the feasibility and effectiveness of coaching parents remotely on child's social communication skills. In addition, the efficiency of the methods and resources required to utilise telemedicine and conduct telemedicine studies in this context were examined. The research consisted of a rapid review, an action research study, and a feasibility study.

7.1 Rapid Review

The COVID-19 pandemic has introduced a definite need to establish the evidence on delivering early interventions remotely to ensure the continuity of the services provided to young autistic children. The rapid review examined the existing evidence on the effectiveness of telemedicine in coaching parents of autistic children to implement naturalistic developmental early interventions (NDI). The findings from the rapid review provided preliminary evidence that telemedicine is an effective approach to coaching parents of young autistic children on NDIs. However, the study showed insufficient evidence for the effectiveness of telemedicine in delivering NDIs on child's social communication behaviours, consistent with previous research. In addition, the quality assessment revealed that all the included studies were at high risk of bias in at least one quality indicator of the risk of bias tools.

7.2 Action Research

The current research is the first to describe SLTs' treatment-as-usual in one of the community-based settings in Riyadh and one of few studies that contributed to understanding the experiences and perceptions of parents of autistic children. The research brought evidence into the experiences of Saudi SLTs in providing EI for autistic children and their families using participatory action research. In addition, the research provided insight into parents' perceptions about EI services, including their involvement and their relationship with the child's SLT. Understanding parents' and SLTs' perspectives about current EI services helped recognise the needs of parents and address the challenges faced by both parents and SLTs in this context.

The findings from the action research showed that the intervention provided by the SLTs at PSMMC-AC was therapist-implemented or hybrid, provided on a one-to-one basis, with no consistent parent training. The study showed that the SLTs faced challenges mainly related to parental involvement and commitment to the intervention. In addition, the nature of the PAR enabled the SLTs to describe the treatment-as-usual and develop an intervention plan which guided the development of a parent-mediated early intervention program used in the feasibility study.

Furthermore, the action research findings showed that parenting an autistic child in the KSA was challenging and effortful, consistent with previous research from other contexts. The study revealed that parents were eager to help their autistic children and expressed efforts to improve their child's behaviours. In addition, the findings suggest professional's collaboration and attributes are vital for continuous parental engagement in the intervention. However, the study showed that participants have mixed views about the intensity and outcomes of the early intervention provided in this context.

7.3 Feasibility Study

The current research investigated the feasibility of using telemedicine to deliver the community-based parent-mediated EI for autistic children below six years developed in the PAR study. The feasibility study examined the implementation of telemedicine in the Saudi context using current resources and infrastructure. The study provided evidence for parents' intention to use, acceptability, and usability of telemedicine in this context. In addition, the study explored parents' acceptability to participate in future telemedicine trials.

The feasibility study revealed high acceptability toward using telemedicine for clinical and research purposes among PSMMC-AC clients. The results support the decision to use videoconferencing and video-feedback method in the intervention studies conducted in this context. The findings support the feasibility of coaching parents of autistic children via telemedicine as evidenced in parents' ability to learn new skills remotely consistent with previous studies. In addition, high levels of telemedicine usability and satisfaction were seen following the intervention. However, the data showed that most parents were unable to engage in weekly coaching sessions. Eight out of 11 participants required 12 or more weeks to complete the intervention instead of nine weeks.

Finally, the research contributed to the development and adaptation of several outcome measures, i.e., the intention to use questionnaire (ITUQ), the telehealth usability questionnaire (TUQ), the parent-child interaction measure (PCIM), the intervention fidelity measure, and the implementation fidelity checklist. To our knowledge, the ITUQ is the first Arabic survey to investigate the acceptability of using telemedicine and video-feedback method with autistic children. Likewise, the adaptation of the TUQ into the Arabic language offered one of few tools used to evaluate the telemedicine experience in Arabic populations. In addition, a new behavioural observation measure of parent-child interaction in an unstructured natural context, i.e., PCIM, was developed. The PCIM is one of the few reliable observational measures that provide the opportunity to count the frequency of parent synchrony, asynchrony, and child's social communication behaviours.

7.4 Contribution to Gaps in the Literature

As discussed in Chapter 1, there is a gap in the literature contributing to autism interventions in Arab countries. Little is known about EI services in the Arab countries, including the KSA. Furthermore, the literature on telemedicine application in the KSA generally and telepractice in autism services, specifically, is limited. To our knowledge, this is the first research to evaluate the feasibility of delivering parent-mediated intervention via telemedicine in the Saudi context. In addition, this research added to our understanding of the practicality of remote coaching and the usability of telemedicine in community-based settings.

In Chapter 1, the need for more high-quality research evaluating the effectiveness of EI provided in community-based settings was highlighted. Findings from the rapid review showed insufficient evidence for the efficacy of telemedicine in delivering NDIs on child's social communication (see Chapter 2). Although the current research did not aim to investigate the effectiveness of the intervention, it is a starting point toward examining the effectiveness of telemedicine in a community-based setting. Moreover, the research provided insight into parents' acceptability of the intervention and taking part in future effectiveness trials. In addition, the feasibility study answered questions like how to successfully implement the intervention in future controlled trials using available resources.

Despite the progress, little work has been done exploring SLTs' practices and perceptions when working with autistic children and their families (see Chapter 3). The current research adds to the literature on SLTs' practices and experiences in delivering EI for autistic children. The action research is the first to describe EI practice in a speech therapy clinic in Riyadh. In addition, the research on parents' perspectives, expectations, and experiences of EI practices in the KSA is minimal (see Chapter 4). The action research is one of few studies conducted in this context to understand the experiences and perceptions of parents of autistic children.

There is a clear gap in measuring parent-child interaction for autistic children under six years in an unstructured natural context (see Chapter 5). Although the current research did not aim to address this gap, the need to develop a behavioural observation measure of parent-child interaction emerged during the planning stage of the feasibility study. Therefore, creating a new behavioural observation measure, the PCIM, is a step to addressing this gap. In addition, the PCIM is the first measure of parent-child dyadic interaction to be tested on Saudi Arabic autistic children.

7.5 Clinical Implications

The evidence from the rapid review on the efficacy of using telemedicine to deliver parent-mediated NDI for autistic children is inconclusive. The study has two main implications for practitioners wishing to deliver NDIs via telemedicine. First, the review showed insufficient evidence of the effectiveness of telemedicine in delivering NDIs on child's social communication. Second, although the findings suggest intervention fidelity can be achieved by coaching parents remotely via telemedicine, the quality of evidence is low. Therefore, at this point, telemedicine must be used with caution or under circumstances where in-person service delivery is not possible until additional evidence is established. Researchers may consider examining the effectiveness of telemedicine as a supplement to in-person parent-mediated NDIs, i.e., a hybrid approach.

Introducing telemedicine to augment traditional in-person service delivery models will potentially increase the accessibility to autism professionals and services. It will help address disparities in accessing autism intervention services by ensuring continuity of services, especially to families situated far from specialised centres. However, findings from the feasibility study suggest practitioners should stay in phone contact with parents for immediate troubleshoot of any technical problems.

Furthermore, the participation rate in the feasibility study was very low (< 11%), possibly because parents did not want to send a video of parent-child interaction. It is not clear whether this conclusion is culture-specific. However, parents' hesitancy to share videos could be solved for clinical purposes by teaching parents how to share the video using sharing screen without the need to transfer it to the therapist. In addition, a low level of engagement in weekly intervention sessions was observed for most participants. On this matter, the action research revealed mixed views on the intensity of the EI in this context. The action research also showed that parenting an autistic child in the Saudi context was stressful and led to increased responsibilities. Based on these findings, practitioners should decide on the frequency of intervention sessions in partnership with the parents and review it regularly to decrease possible demands.

The findings from the action research emphasised parents' need for more support by the SLTs alongside the intervention by actively engaging them in the decision-making process. Supporting parents is expected to enhance their engagement and may perhaps lead to more sessions being attended. Considering these findings, practitioners must effectively utilise a family-centred approach when providing early interventions for autistic children in this context. Further, practitioners must inform the parents about evidence-based interventions and support their decisions when designing the intervention program. Finally, it is crucial for the practitioners to revise and update the intervention program to address child's and family needs and help parents remain engaged in the intervention to ensure continuity of service, e.g., moving from in-person to a hybrid approach when needed.

7.6 Limitations

Rapid reviews have emerged as an efficient tool for generating systematic evidence for health care decision-makers in a short time compared to systematic reviews. Choosing rapid review over a systematic review was driven by the researcher's scholarship time restriction. Despite that, the findings from the rapid review are consistent with previous systematic reviews. The limitation of this design such as the limited number of reviewers and languages included must be considered when interpreting the results. Therefore, further research is needed to examine the effectiveness of telemedicine in delivering NDIs using comprehensive systematic reviews and meta-analyses.

COVID-19 pandemic lockdowns impacted the implementation of the feasibility study. The study design was changed from a nonrandomised feasibility study to a pre-post design. Changes were made to the study design after the intervention was delivered in-clinic to the control group. This major interruption limited our understanding of the feasibility of conducting future intervention trials using current resources and procedures. Thus, future research must address this limitation by involving two cohorts when studying the feasibility and effectiveness of telemedicine in community-based settings in the KSA.

The action research employed a participatory design for the SLTs' study only. Using participatory action research design in parents' study was not possible due to constraints in time and resources, i.e., parents require training to be involved effectively. Active involvement of parents in the action research would empower the parents by engaging them in generating actions to improve the service based on their experiences. In addition, the findings from the action research studies were obtained from semi-structured interviews with the SLTs and parents. Data from the interviews reflect participants reports of their opinions and perceptions of what they perceive was happening, not necessarily what was actually happening. Thus, there is a possible bias of perception among the sample. Further, possible bias may occur due to the researcher's familiarity with the research problem, and their belonging to the research context may have affected the interpretations of the findings.

Finally, most of the measures used were developed for the current research and were not tested before. For example, the PCIM was designed and established interrater reliability but lacked test-retest reliability and external validity. The TUQ was translated into the Arabic language for the purpose of this study. However, further testing of the psychometric properties of the Arabic version of the TUQ is required. The ITUQ was developed and piloted for the feasibility study, but psychometric properties have not been established. Therefore, the measures need to be further tested to confirm our understanding of the findings.

7.7 Future Directions

The ultimate goal is to develop a service delivery model that can increase access to evidence-based EI and promote equity in autism services to all families. Demonstrating the feasibility of delivering parent-mediated intervention via telemedicine in this context is a small but important step toward offering an evidence-based intervention to underserved and mobile populations, i.e., military families. It is crucial to understand how telemedicine can be integrated into established autism services to address barriers and improve outcomes for young autistic children and their families. However, to comprehend the impact of the findings brought out in the current research, future studies must build on these findings by evaluating other key aspects of feasibility, such as the demand and cost-effectiveness of telemedicine in the Saudi context. Researchers may also consider investigating the acceptability of sharing videos of parent-child interaction in other contexts, e.g., other populations inside or outside the KSA.

There continues to be an urgent need to bridge the science-to-service gap globally and address disparities in access to evidence-based EI for young autistic children. More high-quality research to examine telemedicine applications on child's social communication in community-based settings is required. In addition, further research is needed to determine the effectiveness of telemedicine as a supplement and not only as a replacement to in-person parent-mediated interventions. Future research must consider investigating the effectiveness of telemedicine in delivering NDIs before conducting large-scale trials. Moreover, to better understand the implication of the findings, researchers should utilise qualitative study designs to address parents' experiences of telemedicine. Hence, researchers and practitioners should continue to examine the feasibility and effectiveness of telepractice for improving social communication skills in autistic children.

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Appendices

Appendix 1 – Topic Guide for Semi-structured Interviews

Topic guide for Study I of the action research (SLTs):

- Tell me about your experience as SLT.
- How do you think this experience shaped your practice with autistic children?
- Describe your experience at the Autism Centre.
- What do you think about the SLT practice at the Autism Centre?
- Tell me about the early intervention service you provide.
- What factors affect your decision about intervention goals?
- How do you plan your intervention?
- If you wish to change and improve the practice, what will you do?
- Is there anything that you want to add?

Topic guide for Study II of the action research (Parents):

- Tell me about your experience as a mother of an autistic child.
- What are the services that your child had received so far? Are they as expected?
- Describe your experience at the Autism Centre.
- Describe your experience with the SLT services.
- Tell me about your role in the therapy.
- How do you feel about being engaged in the therapy?
- What do you expect from the therapy service provided by the SLTs?
- What changes you expect to happen to your child after the early intervention?
- If you wish to modify something related to the therapy what would you suggest?
- Is there anything that you want to add?

Appendix 2 – Participatory Action Research Data Analysis Method Handout

Data Analysis

Inductive thematic analysis will be used across the data set to analyze the audio-recorded data collected from the semi-structured interviews and the discussions of the self-evaluation therapy checklist. Inductive analysis unlike deductive analysis, which involves coding the data and fitting it into themes based on researchers' theoretical knowledge and interests. Instead, inductive analysis is data-driven and is based strongly on what is said by participants (Braun & Clarke, 2006; Creswell, 2014). Manual coding of the SLTs transcribed interviews' and the development of thematic map will be done in a participatory meeting with all SLTs involved in the study.

"**what counts as a theme?**

A theme captures something important about the data in relation to the research question and represents some level of *patterned response or meaning* within the data set."

In this study, the research aim is *to develop a unified early intervention plan, parent-coaching strategies, and criteria for the intensity and duration of the early intervention service.*

The research question we are trying to answer from the semi-structured interviews with the SLTs is *How different experiences shape SLTs' early intervention practice?*

Points to consider:

1. "There will be a number of instances of the theme across the data set, but more instances *do not necessarily* mean the theme itself is more crucial." So, it is about researchers' judgements.
2. "The importance of a theme is not necessarily dependent on quantifiable measures- but in terms of whether it captures something important in relation to the overall research question."
3. "You can code individual extracts of data in as many different 'themes' as they fit into- so an extract may be uncoded, coded once, or coded many times, as relevant."
4. "You do not have to smooth out or ignore the tensions and inconsistencies within and across data items."

Manual coding steps during the analysis session:

1. First, write notes on the texts you're analysing (usually on the margins) using colored pens to **identify the codes**. Ensure that all data extracts are coded.
2. Second, **match up data extracts with the same codes** by cutting out the text that represents the code from the printed transcribed data of the interview.
3. After matching together data extracts with the same codes, **start sorting different codes into themes**, and collate all the relevant coded data extracts within the identified themes. You might use tables or mind maps. You might need to set themes and sub-themes. You might also set a theme that includes all the data extract that are coded but does not seem to fit any of the created themes.
4. **Review and refine themes.**
   A. Stage one: review at the level of the coded data extracts; read all the collated data extracts for each theme and consider whether they appear to form a coherent

    pattern. If your candidate themes appear to form a coherent pattern, then move to the second stage.
    B. Stage two: consider the validity of individual themes in relation to the data set by re-reading the printed data set. Make sure the themes accurately reflect the meanings evident in the data set as a whole. Code any additional data within the themes that has been missed in earlier coding stages.
5. Finally, **define and name the themes** to ensure there is not too much overlap between themes. Determine what aspects of the data each theme captures, consider how it fits into the whole data set, and in relation to the research question.

Analysis of the written data collected from the checklists and medical documents will involve generating themes that are both data-driven/inductive (i.e., depending on the data) and theory-driven/deductive (i.e., based on researchers' knowledge, themes may emerge from different intervention approaches) (Braun & Clarke, 2006).
Moreover, the data will be analysed explicitly, with no interpretation of the data to a level that is beyond what is said or written (Braun & Clarke, 2006).

Appendix 3 - Thematic Analysis Results from SLTs' Data

Themes	Subthemes	Codes
Services	Intensity and design	Intensity of intervention sessions
		Intervention session structure
		Parent-training
		Home-program follow-up tools
	Decision-making processes	ASD severity
		Co-occurring (ADHD)
		IQ level
		Enrollment in educational centre
		Child's age
		Child's language level
		Parents' involvement
		Parents' preference
		Parents' educational level
		Family location
		Consulting SLTs
		Consulting other team members
Challenges		Parental engagement in intervention
		Parents not attending intervention sessions
		Attending more than one intervention session per visit
		Other challenges
Development		Criteria for the intensity of sessions
		Criteria for the duration of the intervention program
		Generalization of intervention goals
		Suggestions to improve SLT services
		Suggestions to enhance other services

Appendix 4 – Intention to Use Questionnaire (Arabic)

University of Reading

برنامج الأمير محمد بن سلمان للتوحد واضطرابات النمو
PRINCE MOHAMMED BIN SALMAN PROGRAM
FOR AUTISM AND DEVELOPMENTAL DISORDERS

School of Psychology and Clinical
Language Sciences
Whitenights
Reading, RG6 6AL

استطلاع مدى تقبّل أهالي الأطفال المصابين باضطراب طيف التوحد لاستخدام تقنيات الطب الإتصالي واستراتيجية التقييم بواسطة الفيديو

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هذه الاستبانة جزء من مشروع بحثي عن استخدام الطب الاتصالي في خدمة الأطفال المصابين باضطراب طيف التوحد وأسرهم. نريد معرفة ما اذا كان مقدمي الرعاية للأطفال المصابين بالتوحد سوف يستخدمون خدمات الطب الاتصالي في حال توافرها.

ما هو الطب الاتصالي؟ هو إيصال خدمات الرعاية الصحية عن بُعد باستخدام طرق التواصل الالكترونية لتحسين حالة المريض الصحية. على سبيل المثال، الحصول على خدمات الرعاية الصحية دون الحاجة إلى الحضور الشخصي إلى العيادة أو المستشفى، عن طريق مقابلة الأخصائي المعالج باستخدام المكالمات المرئية والمكالمات الهاتفية وتطبيقات الهواتف الذكية.

في بحثنا، سنستخدم الطب الاتصالي لنجعل التدخل المبكر أسهل توفراً للأطفال المصابين باضطراب طيف التوحد وأسرهم. يشمل التدخل المبكر تدريب الآباء والأمهات على كيفية مساعدة أطفالهم على التواصل الاجتماعي بأكثر الطرق فعالية. سوف يطلب من الوالدين تسجيل مقطع فيديو للأخصائي المعالج يوضح تطبيقهم للاستراتيجيات المعطاة في التدريب.

تبعاً لذلك، سنكون شاكرين جداً لك لإكمالك هذه الاستبانة. لن تأخذ أكثر من ٥ دقائق من وقتك. هذه الاستبانة مجهولة تماماً، يرجى عدم كتابة اسمك في أي مكان على هذه الاستبانة.

تمت مراجعة هذا الاستبيان والموافقة عليه من فريق أخلاقيات البحث في الجامعة وفي مدينة الأمير سلطان الطبية العسكرية. أشكرك جزيل الشكر على وقتك ومساعدتك.

استبانة مدى التقبّل

مكان السكن: ....

تمت التعبئة من قبل: ○ الأم ○ الأب ○ آخر

القسم الأول- التجارب السابقة.	**نعم**		**لا**		
سمعت عن الطب الاتصالي من قبل.					
استخدمت خدمات الطب الاتصالي من قبل.					
لو قمت بإجابة السؤال الثاني ب"نعم"، يرجى ذكر أي نوع من وسائل الطب الاتصالي قمت باستخدامه؟					
القسم الثاني- نية الاستخدام.	**أوافق بشدة**	**أوافق**	**لا أوافق ولا أرفض**	**لا أوافق**	**لا أوافق بشدة**
استخدام الطب الاتصالي لخدمة المريض فكرة جيدة.					
أعتقد أن الطب الاتصالي قد يكون مفيداً في خدمة طفلي.					
أنوي استخدام الطب الاتصالي لخدمة طفلي اذا أصبح متوفراً.					
أعتقد أن لدي القدرة على استخدام الطب الاتصالي لمساعدة طفلي.					
الأشخاص المهمين بالنسبة لي سوف يسمحون باستخدامي للطب الاتصالي.					
عند ضمان الخصوصية، لا مانع لدي من استخدام فيديو خاص بي وبطفلي مع الأخصائية كجزء من الطب الاتصالي.					
القسم الثالث- في تجربة استخدام الطب الاتصالي مع حالات اضطراب طيف التوحد سوف يتم استخدام مقاطع فيديو توضح التفاعل بين الوالدين والطفل المصاب لإعطائهم التوجيهات كجزء من التدريب.					
سأكون مهتماً بالمشاركة في البحث المتضمن على تجربة الطب الاتصالي في التدخل المبكر لاضطراب طيف التوحد.					
لا مانع لدي من مشاركة مقطع فيديو مع الأخصائية الباحثة في جلسة الطب الاتصالي.					
لا مانع لدي من مشاركة مقطع فيديو مع الأخصائية الباحثة ومع باحثة ثانية في جلسة الطب الاتصالي.					
سأسمح للأخصائية الباحثة بحفظ الفيديو لمشاهدته مرة أخرى في وقت لاحق. *ملاحظة: سيتم حذف الفديو بعد ذلك.*					
سأسمح للأخصائية الباحثة بحفظ الفيديو لمشاهدته مرة أخرى في وقت لاحق مع باحثة ثانية. *ملاحظة: سيتم حذف الفديو بعد ذلك.*					

Appendix 5 – Parent-Child Interaction Measure (PCIM) Initial Draft

Definitions of Parent and Child Codes:

Key	Child Code	Definition
J	Initiated joint attention (IJA)	Spontaneous initiation of joint attention by shifting her/his eye gaze from an object to the parent, for the purpose of sharing a topic or focus with the parent, either action, feelings/emotions, experiences, games or objects. It involves a reference to the parent and the object by coordinated looking, showing, giving, body orientation or acknowledgement of the other's focus. - Do NOT use this code if the child's initiation may have been elicited by parent's movement or verbalization. - The child does NOT have to look back to the object. - Use this code if the child IJA using eye gaze accompanied with pointing for the purpose of showing.
R	Responding to joint attention (RJA)	Response to joint attention elicited by the parent. The child must shift her/his eye gaze following parent's eye gaze or pointing gesture to an object, for the purpose of responding to a topic or focus with the parent. It involves a reference to the parent and the object by coordinated looking, showing, sharing or giving, body orientation or acknowledgement of parent's focus.
M	Imitation	This code is used for child's intent to imitate the parent using physical, gestural, vocal and speech behaviours with appropriate intonation. - This code of imitation must always be spontaneous (not physically prompted). - This code is used for the imitation of conventional and unconventional gestures. Conventional gestures are gestures with social meaning e.g., nodding instead of "yes" or shaking head for "no". Unconventional gestures are gestures with no social meaning e.g., drinking out of a toy cup. - Child's attempt to repeat parent's speech or vocalizations with identical intonation is considered echolalia, and must NOT be scored using this code.
C	Initiated social-communication act (ISCA)	This code is used for any meaningful context-related communication act initiated by the child for the purpose of socializing. - Use this code for any communication act verbal or non-verbal in which the child is communicating for the purpose of sharing, giving or showing e.g., pointing for the purpose of sharing an event or pointing for the purpose of showing the parent an object without coordinated looking. - Use this code for any verbal communicative act e.g., comments produced by the child for the purpose of spontaneously referring to an event, object, person, or action, with or without coordinated looking. - Self-directed verbal communicative act must NOT be coded unless they are clearly part of a social interaction with the parent.
N	Maintaining social interaction (MSI)	This code is used for any meaningful context-related communication act verbal or non-verbal produced by the child to maintain an interaction with the parent with or without coordinated looking. - Use this to code every turn-taking exhibited by the child to maintain social interaction with the parent e.g., the child imitated the parent

		by drinking from a toy cup (if the parent did not ask the child, it will be coded as imitation, if the parent asked the child to take-turn, it will be coded as maintain social interaction MSI) then, if the child gives the parent the cup to take-turn, it will be coded as another attempt to MSI.
T	Terminating social interaction (TSI)	This code is used when a social interaction is terminated by the child. The child may end a social interaction by running away from the parent, shifting his attention to a new object or action, or by using avoidance behaviours e.g., crying or lying on the floor.
I	Initiated request (IR)	This code is used for any communicative act initiated by the child, verbal or non-verbal where an object or action (e.g., to open a snack or to blow bubbles) is requested. This code is also used when the child requests a game or activity, i.e., tickling.
P	Prompted request (PR)	This code is used for any communicative act verbal or non-verbal prompted by the parent, where an object or action (e.g., to open a snack or to blow bubbles) is requested. - Use this code when the parent prompts the child either verbally or non-verbally, including full or partial physical prompting and gestural prompting.
Parent Code		Definition
A	Asynchronous communication act	This code is used for any asynchronous communicative act verbal or non-verbal used to direct or instruct the behaviour of the child or used to elicit a direct response from the child to a question e.g., command or question.
S	Synchronous communication act	This code is used for any synchronised face-to-face interaction aimed to support and facilitate the behaviour of the child for the purpose of initiating and maintaining the flow of the interaction and child's attention by acknowledging child's focus of interest and using timely reciprocal communication. - This code is used for any verbal communicative act produced by the parent, including comments, statements, and acknowledgement. - This code is also used for any non-verbal communicative act produced by the parent, including movements and facial expressions. - Use this code when parent imitate the child's either verbally or through movements and gestures. - This code is used ONLY when child is attending or parent must wait until the child is refocused, pacing their actions to maximise the child's attention i.e., pausing to give the child a chance to act.
Parent/Child Code		Definition
D	Dyadic interaction (DI)	This code is used when a synchronous communication act followed by maintaining social interaction (MSI) or responding to joint attention (RJA).

Appendix 6 – Intervention Program

Session #	Child Goals	Parent Learning Outcomes
One	1. Improve joint attention (Green et al., 2010; Rogers, Dawson & Vismara, 2012, p.63).	*By the end of this session the parent must be able to facilitate child's joint attention by:* 1. Adjusting the environment by minimizing distractions (Ingersoll & Dvortcsak, 2010, p.72; Rogers et al., 2012, p.65). 2. Identifying what the child is attentive to (Green et al., 2010; Rogers et al., 2012, p.65; Sussman, 2012, p.2). 3. Trying to be close, on the same level, and face to face with the child during play (Rogers et al., 2012 p.152). 4. Following child's lead (Ingersoll & Dvortcsak, 2010, p.77; Rogers et al., 2012 p.65; Sussman, 2012, p.85) 5. Imitating child's sounds, gestures, facial expressions, actions, and words (Ingersoll & Dvortcsak, 2010, p.85; Rogers et al., 2012, p.84; Sussman, 2012, p.102). 6. Pause and wait.

Examples of activities:

- **Playing time:** play with the child in the same way he plays (opening and closing drawers – lining up cars – spinning wheels of the cars) (ESDM)
- **Playing time (bubble example):** let the child catch the bubble, pop up the bubble and hold the bubble away to give the child opportunity to look to the bubble then to you (Griffin & Sandler, 2009, p.64).
- **Playing time (balloon example):** by blowing a balloon up gradually, pausing and waiting between each breath with exaggerated facial expressions during blowing (Griffin & Sandler, 2009, p.68).

Session #	Child Goals	Parent Learning Outcomes
Two	1. Engage in dyadic joint activities (Rogers et al., 2012 p.91; Rogers & Dawson, 2010 p.110; Sussman, 2012, p.137).	*By the end of this session the parent must be able to enhance child's engagement through playing by:* 1. Finding reciprocal parent-child activity i.e., tickling, peek a boo, flying through the air (Rogers et al., 2012, p.95; Sussman, 2012, p.161-187). 2. Keeping parent turn short so the child does not lose interest. 3. Pause and wait. 4. Adding appropriate sound effect i.e., language or vocalization (Green et al., 2010; Rogers et al., 2012 p.111).

Examples of activities:

- **People play:** horse game – tickling – swinging – peekaboo.
- **Bathing time:** use bubbles in the tub to place in your child arm; thin rinse away by pouring water and repeat (Rogers & Dawson, 2010, p.98).
- **Dressing time:** peekaboo with a shirt or pants (Rogers & Dawson, 2010, p.98).

Session #	**Child Goals**	**Parent Learning Outcomes**
Three	1. Functional/pretending play (Rogers et al., 2012, p.263; Sussman, 2012, p.364).	*By the end of this session the parent must be able to enhance child's playing skills by:* 1. Selecting double sets of toys or objects to teach functional play acts by imitation (Rogers et al., 2012, p.263; Rogers & Dawson, 2010, p.147). 2. Trying to be close up, on the same level, and face to face with the child during play (Rogers et al., 2012 p.152). 3. Providing appropriate physical prompt if needed and fading to reach spontaneous response (Rogers et al., 2012, p.310; Rogers & Dawson, p.164, 2010). 4. Adding appropriate sound effect i.e., language or vocalization (Green et al., 2010; Rogers et al., 2012 p.111).

Examples of activities for functional play:

- **Mealtime:** using feeding utensils, encourage the child to feed you a bite using her spoon. Also show the child how to feed a doll with your spoon.
- **Story time:** have a doll or animal sit beside your child, show pictures and label them for you child, then for the doll.

Examples of activities for functional play:

- **Sand and water play**: build sand caves for toy animals or people using plastic containers; dig a swimming hole or use cars and trucks to make roads.
- **Play with boxes:** with a little imagination, boxes can be turned into cars, planes, trains, and rocket.
- **Dress-up**: create hats from ice-cream containers, shoes from tissue boxes, robes from old sheets or an elephant trunk from old stockings.
- **Finger puppet play:** have your child come up with a story and script and characters and use finger puppets to put on a play.
- **Pretend to be a doctor with stuffed animals:** pretending to be a doctor and giving their stuffed animal friends checkups and shots.

Session #	Child Goals	Parent Learning Outcomes
Four	1. Turn-taking (Ingersoll & Dvortcsak, 2010, p.112; Sussman, 2012 p.111).	*By the end of this session the parent must be able to teach their child to take turns by:* 1. Choosing an activity that has a very short waiting period (Ingersoll & Dvortcsak, 2010, p.115). 2. Parent may choose to teach turn taking through daily routine activities i.e., dressing, eating, and tooth brushing (Sussman, 2012, p.260). 3. Using a visual cue to indicate whose turn it is and use turn taking language (my turn, your turn) (Sussman, 2012, p.121). 4. Waiting for the child to communicate his turn (Ingersoll & Dvortcsak, 2010, p.115). 5. Modelling turn taking with another child or sibling (Sussman, 2012, p.116).

Examples of activities for turn-taking:

- **Mealtime:**
  - <u>During the meal</u>: the mother takes a bite and saying "my turn", then the child takes another bite and saying "your turn"
  - <u>At the end of the meal (cleaning up):</u> The mother first takes the spoon and put it in the tray then help the child to take the plate and put it in the tray, after that the mother will take the cup and also put it in the tray….. continue. Add some language "My turn .. spoon" – "your turn .. plate".
- **Dressing time:**
  - The mother combs her hair and saying "my turn ..comb", then give the brush to the child help him/her to comb his/her hair and saying "your turn .. comb".
  - The mother will put the perfume and saying "my turn .. perfume" then give it to the child help him/her put the perfume and saying "your turn .. perfume".
  - The mother put on one sock "my turn" you put on one sock "your turn".
- **Playing time (car example):** taking the car from the child and saying "my turn", keep it short and return the car to the child and saying "your turn".
- **Playing time (ball example):** to play with the child handball, keeping in mind short turns to keep the child interested. (Ingersoll & Dvortcsak, 2010, p.52)
- **Playing time (Legos example):** to take turns with the child during build up Legos.

Session #	**Child Goals**	**Parent Learning Outcomes**
Five	1. Imitation of adult's non-verbal and verbal communication (Rogers et al., 2012, p.166).	*By the end of this session the parent must be able to teach their child to imitate by:* 1. Selecting double sets of toys or objects and giving the child chance to start playing then imitate child's movements and vocalizations and expect the child to imitate back. 2. Adding appropriate sound effect i.e., language or vocalization (Rogers & Dawson, 2010, p.138; Sussman, 2012, p.117). 3. If needed: starting with appropriate prompt (e.g., physical or visual) and fading to reach spontaneous response. 4. Reinforcing child's attempts to imitate adult's behaviour and communication (Rogers et al., 2012, p.180).

Examples of activities for imitation:

- **Waving "bye bye":** every time he leaves a place.
- **Nursery rhymes**: "if you are happy and you know claps your hand" – "the wheels on the bus goes round and round".
- **Meal time: /?**amm/ sound every time the child eat - /?ah/ sound for hot food - adding drinking sound.
- **Playing time (bubbles example):** to pop bubble using different actions (with fingers or clapping hands together or stomping on them with feet) and adding /pa/ sound.

Session #	Child Goals	Parent Learning Outcomes
Six	1. Request non- verbally by (give me) gesture (Green et al., 2010; Rogers & Dawson, 2010, p.163; Rogers et al., 2012, p.140).	*By the end of this session the parent must be able to train the child to request non-verbally by:* 1. Selecting a highly preferred object (Rogers et al., 2012, p.235; Rogers & Dawson, 2010, p.161; Sussman, 2012, p.56). 2. Creating lots of practice opportunities; build in barriers so the child needs help to practice "give me" gesture (Ingersoll & Dvortcsak, 2010, p.126; Rogers et al., 2012, p.143; Rogers & Dawson, 2010, p.163; Sussman, 2012, p.86). 3. Trying to be close up, on the same level, and face to face with the child (Rogers et al., 2012 p.152). 4. Developing a balance between parent's and child's initiations i.e., do less so the child does more (Rogers et al., 2012, p.141). 5. Pause and wait (Rogers et al., 2012, p.142; Rogers & Dawson, 2010, p.163; Sussman, 2012, p.88). 6. Starting with appropriate prompt (e.g., physical or visual) and fading to reach spontaneous response (Rogers et al., 2012, p.310; Rogers & Dawson, p.164, 2010). 7. Increasing the distance (Rogers et al., p.234, 2012; Sussman, 2012, p.86).

Examples of activities:

- **Mealtime:** requesting his favorite food non-verbally by using “Give me” gesture.
- **Bathing time:** requesting bath toys non-verbally by using “Give me” gesture (Rogers & Dawson, 2010, p.142).
- **Playing time (Legos example):** requesting the Legos one by one to build up.

Session #	**Child Goals**	**Parent Learning Outcomes**
Seven	1. Pointing for requesting (Rogers & Dawson, 2010, p.165; Rogers et al., p.235, 2012), and for sharing and showing purposes (Rogers & Dawson, 2010, p.166; Rogers et al., 2012, p.237).	*By the end of this session the parent must be able to teach their child to point to meet her needs and to socialize by:* 1. Selecting a highly preferred object (Rogers et al., 2012, p.235; Rogers & Dawson, 2010, p.161; Sussman, 2012, p.56) 2. Creating lots of practice opportunities; build in barriers so the child needs help to get the object because it is out of her reach (Green et al., 2010; Rogers et al., 2012, p.234; Sussman, 2012, p.86). 3. Teaching the child how to point to the object she needs (Rogers et al., 2012, p.234). 4. Starting with appropriate prompt (e.g., physical or visual) and fading to reach spontaneous response (Rogers et al., 2012, p.310; Rogers & Dawson, p.164, 2010). 5. Increasing the distance (Rogers et al., p.234, 2012; Sussman, 2012, p.86). 6. Teaching the child how to point to objects to share experience (to show or comment) (Rogers et al., p.237, 2012).

Examples of activities for pointing:

- **Story time:** when you read books to your child point to the pictures or specific objects you see.
- **Bubble play:** when you blow bubbles for your child and pop the bubbles with your fingers.
- **Daily life activities:** when pointing to things that are close by, like an interesting toy that’s nearby when you are playing together, or a motivating snack that’s just slightly out of reach. You can try pointing to things that are a little farther away, such as something interesting across the room.
- **Play pointing games:** point to your body parts and the child’s body parts and name it.

Session #	**Child Goals**	**Parent Learning Outcomes**
Eight	1. Improve language skills (Ingersoll & Dvortcsak, 2010, p.96; Rogers et al., 2012, p.303).	*By the end of this session the parent must be able to stimulate child's language by:* 1. Trying to be close, on the same level, and face to face with the child (Rogers et al., 2012 p.152). 2. Avoid questions (Ingersoll & Dvortcsak, 2010, p.101). 3. Model language around child's focus of interest (Ingersoll & Dvortcsak, 2010, p.100). 4. Naming the targeted object using clear and exaggerated language i.e., short and clear phrases (Ingersoll & Dvortcsak, 2010, p.104; Sussman, 2012, p.196). 5. Provide focused stimulation by using the same words (Ingersoll & Dvortcsak, 2010, p.104). 6. Training the child to follow simple commands through daily routine activities i.e., dressing, eating, and tooth brushing (Rogers et al., 2012, p. 310). 7. Pause and wait (Rogers et al., 2012, p. 310; Sussman, 2012, p.86). 8. Starting with appropriate prompt (e.g., physical or visual) and fading to reach spontaneous response (Rogers et al., 2012, p.310; Rogers & Dawson, p.164, 2010).

Examples of activities:

- **Mealtime:**
  - Preparing for the meal: open the refrigerator. (Ingersoll & Dvortcsak, 2010, p.104)
  - During eating: give me one piece – hold the water or juice container and say "give me your cup". (Ingersoll & Dvortcsak, 2010, p.91)
  - At the end of the meal: clean up – give me "spoon – plate – fork – cup" – put it in the garbage – wash your hand.
- **Dressing time:** give me sock – give me shoes – comb your hair – wear your sock – wear your shoes – wear your shirt – wear your pants.
- **Tooth brushing time:** take the brush – put the toothpaste - Brush your teeth – rinse – wash your hand.
- **Hand washing time:** open the tap — put the soap – wash your hands – take the tissue – wipe your hand – put it in the garbage.
- **Bathing time:** give your child directions to help prepare for the bath e.g., get your towel – get the soap – turn on the water. (Ingersoll & Dvortcsak, 2010, p.91).

Appendix 7 - Feasibility Study Demographics Form

دراسة جدوى تدريب أمهات أطفال ذوي اضطراب التوحد على تطبيق علاج للتواصل الاجتماعي عن بعد بواسطة الطب الاتصالي

معلومات المشاركة

اسم المشاركة:	
العمر:	
المستوى التعليمي:	☐متوسط ☐ثانوي ☐دبلوم ☐جامعي ☐دراسات عليا
الوظيفة (إن وجد):	
الحالة الإجتماعية:	☐متزوجة ☐منفصلة ☐أرملة
الجنسية:	
الأصل العرقي:	☐عربي ☐إفريقي ☐غير ذلك
مقر الإقامة (المدينة):	
عدد الأخوة:	
هل يوجد من أفراد العائلة من هو من ذوي الاحتياجات الخاصة أو يحتاج رعاية خاصة مثل كبار السن؟ اذا كان الجواب نعم، الرجاء ذكر الإعاقة أو المشكلة الصحية.	
هل الأم المشاركة لديها مساعدة في البيت؟ مربية أو خادمة أو ابن أو ابنه يقدمون المساعدة؟	
هل الطفل المشارك يأخذ أي أدوية؟ الرجاء ذكرها ووصف الجرعة.	
التحاق الطفل بمدرسة أو مركز:	☐مدرسة عادية ☐مركز للتوحد ☐مركز احتياجات خاصة ☐فصول دمج مع أطفال طبيعيين ☐غير ملتحق
هل تلقى الطفل جلسات تخاطب أو جلسات سلوكية أثناء الدراسة؟ الرجاء ذكر التفاصيل.	
مستوى الطفل اللغوي:	☐غير ناطق ☐ناطق (كلمات مفردة) ☐ناطق (جُمل)
كم كان الوقت المستغرق في رعاية الطفل المشارك من ناحية تطبيق التدريبات وتعزيز التواصل واللعب خلال اليوم؟	
وجود صعوبة في المواصلات:	نعم ☐لا☐

Appendix 8 – Telehealth Usability Questionnaire (English)

University of Pittsburgh
School of Health and Rehabilitation Sciences

6051 Forbes Tower
Pittsburgh, Pennsylvania 15260
412-383-6649

TELEHEALTH USABILITY QUESTIONNAIRE (TUQ)

		N/A		1	2	3	4	5	6	7	
1.	Telehealth improves my access to healthcare services.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
2.	Telehealth saves me time traveling to a hospital or specialist clinic.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
3.	Telehealth provides for my healthcare need.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
4.	It was simple to use this system.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
5.	It was easy to learn to use the system.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
6.	I believe I could become productive quickly using this system	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
7.	The way I interact with this system is pleasant.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
8.	I like using the system.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
9.	The system is simple and easy to understand.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
10.	This system is able to do everything I would want it to be able to do.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
11.	I can easily talk to the clinician using the telehealth system.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
12.	I can hear the clinician clearly using the telehealth system.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
13.	I felt I was able to express myself effectively.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
14.	Using the telehealth system, I can see the clinician as well as if we met in person.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
15.	I think the visits provided over the telehealth system are the same as in-person visits.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
16.	Whenever I made a mistake using the system, I could recover easily and quickly.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
17.	The system gave error messages that clearly told me how to fix problems.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
18.	I feel comfortable communicating with the clininician using the telehealth system.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
19.	Telehealth is an acceptable way to receive healthcare services.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE

20.	I would use telehealth services again.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
21.	Overall, I am satisfied with this telehealth system.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE

Please provide comments about the telehealth system:

Appendix 9 – Telehealth Usability Questionnaire (Arabic)

University of Pittsburgh
School of Health and Rehabilitation Sciences

6051 Forbes Tower
Pittsburgh, Pennsylvania 15260
412-383-6649

استبانة سهولة استخدام الطب الاتصالي

		غ / م		1	2	3	4	5	6	7	
1	الطب الاتصالي يحسن من وصولي إلى خدمات الرعاية الصحية.	☐	لا أوافق	☐	☐	☐	☐	☐	☐	☐	موافق
2	الطب الاتصالي يوفر علي الوقت المبذول في السفر إلى المستشفى أو العيادة المتخصصة.	☐	لا أوافق	☐	☐	☐	☐	☐	☐	☐	موافق
3	الطب الاتصالي يزودني باحتياجي من الرعاية الصحية.	☐	لا أوافق	☐	☐	☐	☐	☐	☐	☐	موافق
4	كان استخدام هذا النظام بسيطاً.	☐	لا أوافق	☐	☐	☐	☐	☐	☐	☐	موافق
5	كان من السهل تعلم استخدام النظام.	☐	لا أوافق	☐	☐	☐	☐	☐	☐	☐	موافق
6	أعتقد انه يمكنني أن أصبح منتجاً بسرعة باستخدام هذا النظام.	☐	لا أوافق	☐	☐	☐	☐	☐	☐	☐	موافق
7	الطريقة التي أتفاعل بها مع هذا النظام مرضية.	☐	لا أوافق	☐	☐	☐	☐	☐	☐	☐	موافق
8	أحب استخدام النظام .	☐	لا أوافق	☐	☐	☐	☐	☐	☐	☐	موافق
9	النظام بسيط وسهل الفهم .	☐	لا أوافق	☐	☐	☐	☐	☐	☐	☐	موافق
10	هذا النظام قادر على القيام بكل ما أريد منه القيام به.	☐	لا أوافق	☐	☐	☐	☐	☐	☐	☐	موافق
11	يمكنني التحدث بسهولة إلى الممارس الصحي بواسطة نظام الطب الاتصالي.	☐	لا أوافق	☐	☐	☐	☐	☐	☐	☐	موافق
12	يمكنني سماع الممارس الصحي بوضوح بواسطة نظام الطب الاتصالي.	☐	لا أوافق	☐	☐	☐	☐	☐	☐	☐	موافق
13	شعرت بأنني قادر على التعبير عن ذاتي بشكل فعال.	☐	لا أوافق	☐	☐	☐	☐	☐	☐	☐	موافق
14	باستخدام نظام الطب الاتصالي، أستطيع رؤية الممارس الصحي كما لو أنني قابلته شخصياً.	☐	لا أوافق	☐	☐	☐	☐	☐	☐	☐	موافق
15	أعتقد أن الزيارات المقدمة عبر نظام الطب الاتصالي تعادل الزيارات الشخصية.	☐	لا أوافق	☐	☐	☐	☐	☐	☐	☐	موافق
16	كلما أخطأت في استخدام النظام، أستطيع تعديل الخطأ بسهولة وبسرعة.	☐	لا أوافق	☐	☐	☐	☐	☐	☐	☐	موافق
17	أعطى النظام رسائل عطل أرشدتني بوضوح إلى كيفية إصلاح المشاكل.	☐	لا أوافق	☐	☐	☐	☐	☐	☐	☐	موافق
18	أشعر بالراحة أثناء التواصل مع الممارس الصحي باستخدام نظام الطب الاتصالي.	☐	لا أوافق	☐	☐	☐	☐	☐	☐	☐	موافق

19	الطب الاتصالي طريقة مقبولة لتلقي خدمات الرعاية الصحية.	☐	لا أوافق ☐ ☐ ☐ ☐ ☐ ☐ ☐ موافق
20	أود استخدام خدمات الطب الاتصالي مجدداً.	☐	لا أوافق ☐ ☐ ☐ ☐ ☐ ☐ ☐ موافق
21	بشكل عام، أنا راض عن نظام الطب الاتصالي.	☐	لا أوافق ☐ ☐ ☐ ☐ ☐ ☐ ☐ موافق

يرجى تزويدنا بتعليقاتك حول نظام الطب الاتصالي:

Appendix 10 – Frequency Rating Results for Intervention Fidelity

#	Strategy	ED13			FS12			FT14			GA18		
		FA	NA	PA	FA	NA	PA	FA	NA	PA	FA	NA	PA
1	1. Adjusting environment.	1	0	0	0	0	1	0	1	0	1	0	0
	2. What child's is attentive to.	1	1	1	1	2	2	2	0	1	1	0	0
	3. Same level, face-to-face.	1	0	0	1	0	0	5	2	7	1	0	0
	4. Follow child's lead.	5	3	0	1	5	0	2	8	1	4	0	1
	5. Imitating the child.	4	0	0	0	2	0	7	0	13	8	2	1
	6. Pause & wait.	4	1	0	0	5	0	4	9	2	1	1	0
2	1. Finding reciprocal activity.	8	0	0	3	0	0	4	0	1	2	0	0
	2. Keeping parent turn short.	23	0	0	4	1	1	19	0	8	2	1	3
	3. Pause & wait.	16	7	1	3	1	2	17	0	9	3	3	5
	4. Adding sound effect.	6	0	1	8	4	6	1	0	0	5	1	0
3	1. Double sets of toys.	3	1	0	0	2	1	2	0	0	0	2	0
	2. Same level, face to face.	1	0	0	1	0	0	3	0	0	2	0	0
	3. Appropriate prompt.	13	2	1	4	1	2	0	3	0	4	2	0
	4. Adding sound effect.	19	5	10	13	1	3	0	0	1	41	3	1
4	1. Choosing short activity.	7	0	0	1	0	0	3	0	0	2	0	0
	2. Apply goal using ADL.	M	M	M	M	M	M	1	0	0	2	0	0
	3. Using visual cue.	25	0	4	0	2	3	21	0	4	7	5	2
	4. Waiting for the child.	2	11	0	0	5	0	16	0	0	2	3	1
	5. Modelling with another chid.	7	0	0	M	M	M	0	1	0	M	M	M
5	1. Double sets of toys.	4	3	0	0	1	0	0	2	0	3	0	0
	2. Adding sound effect.	12	0	4	9	4	1	1	0	0	2	0	1
	3. Appropriate prompt.	15	0	0	1	4	1	9	0	40	1	0	1
	4. Reinforcing child's imitation.	4	7	14	1	1	0	7	2	0	2	0	0
6	1. Selecting preferred object.	3	0	0	1	1	0	1	0	0	2	0	0
	2. Creating opportunities.	14	1	2	0	3	7	6	0	0	9	1	1
	3. Same level, face-to-face.	1	0	0	1	0	0	1	0	0	2	0	0
	5. Pause & wait.	4	0	1	0	0	3	4	2	1	5	1	2
	6. Appropriate prompt.	1	5	5	0	4	0	3	0	2	1	7	0
	7. Increase distance.	M	M	M	M	M	M	M	M	M	M	M	M
7	1. Selecting preferred object.	1	0	1	0	2	1	2	0	0	1	0	0
	2. Creating opportunities.	5	0	0	2	4	0	1	0	1	0	3	3
	3. Teaching how to point.	M	M	M	M	M	M	M	2	0	5	2	0
	4. Appropriate prompt.	4	0	0	1	1	0	7	1	0	3	2	0
	5. Incease distance.	2	0	0	0	0	1	0	2	0	0	1	0
	6. Point to share experience.	1	0	0	M	M	M	1	0	0	M	M	M
8	1. Same level, face-to-face.	3	1	1	1	0	0	2	0	0	0	1	0
	2. Avoid questions.	3	0	0	3	0	0	0	4	0	1	0	0
	3. Model language around child's focus.	31	5	1	5	0	0	0	2	0	1	1	0
	5. Use same words.	4	0	0	2	0	0	1	0	0	M	M	M
	6. Follow commands using ADL.	3	0	0	3	0	2	M	M	M	M	M	M
	7. Pause & wait.	5	0	1	0	3	0	5	1	2	0	1	0
	8. Appropriate prompt.	5	0	0	1	1	3	11	0	0	0	1	0
Sum		271	54	48	71	60	40	169	43	93	76	43	20
Total opportunities		373			171			305			139		
FA strategies %		73%			42%			55%			55%		
FA+PA		319			111			262			96		
FA+PA %		86			65			86			69		

#	**Strategy**	**JB20**			**NF23**			**RF26**			**TA16**		
		FA	**NA**	**PA**	**FA**	**NA**	**PA**	**FA**	**NA**	**PA**	**FA**	**NA**	**PA**
1	1. Adjusting environment.	1	0	7	0	3	0	0	4	2	0	1	0
	2. What child's is attentive to.	4	0	0	1	4	0	0	1	2	1	0	0
	3. Same level, face-to-face.	1	0	0	2	2	0	0	0	3	0	0	1
	4. Follow child's lead.	4	0	0	1	1	0	0	3	1	1	3	0
	5. Imitating the child.	1	2	0	0	1	0	0	2	0	0	8	0
	6. Pause & wait.	1	4	0	0	1	0	0	3	1	1	13	8
2	1. Finding reciprocal activity.	2	0	1	1	0	1	2	0	0	4	0	1
	2. Keeping parent turn short.	27	4	0	1	1	0	3	0	0	3	1	0
	3. Pause & wait.	3	0	0	1	2	0	3	0	0	0	10	1
	4. Adding sound effect.	36	0	5	1	0	0	2	0	1	9	2	1
3	1. Double sets of toys.	2	0	0	2	0	0	0	1	0	2	0	1
	2. Same level, face to face.	1	1	0	2	0	0	0	1	1	2	0	0
	3. Appropriate prompt.	3	1	0	7	1	0	2	1	2	0	14	0
	4. Adding sound effect.	12	0	0	9	0	0	1	2	2	5	13	7
4	1. Choosing short activity.	2	0	0	2	0	0	3	0	0	1	0	0
	2. Apply goal using ADL.	M	M	M	3	0	0	2	0	0	M	M	M
	3. Using visual cue.	15	7	0	0	8	0	0	3	0	5	12	2
	4. Waiting for the child.	6	4	0	3	0	0	0	3	0	1	13	0
	5. Modelling with another chid.	M	M	M	3	1	0	M	M	M	0	0	1
5	1. Double sets of toys.	0	1	0	0	1	0	0	1	0	0	1	1
	2. Adding sound effect.	2	0	0	5	1	0	1	0	2	23	3	19
	3. Appropriate prompt.	0	2	0	0	4	0	0	1	0	1	1	19
	4. Reinforcing child's imitation.	0	0	0	3	0	0	1	0	0	4	2	0
6	1. Selecting preferred object.	3	0	0	2	0	0	0	0	1	1	0	2
	2. Creating opportunities.	11	6	0	2	0	0	0	2	2	1	2	0
	3. Same level, face-to-face.	1	0	0	2	0	0	0	2	0	0	0	1
	5. Pause & wait.	5	2	0	3	0	0	0	0	3	0	2	3
	6. Appropriate prompt.	6	0	5	4	2	0	0	2	2	0	6	0
	7. Increase distance.	M	M	M	M	M	M	M	M	M	M	M	M
7	1. Selecting preferred object.	2	1	0	2	0	0	1	0	0	1	0	1
	2. Creating opportunities.	6	0	0	4	0	0	3	0	1	1	0	0
	3. Teaching how to point.	1	0	0	3	0	0	0	1	1	1	0	4
	4. Appropriate prompt.	3	0	5	2	1	0	2	2	3	5	0	3
	5. Increase distance.	1	0	0	0	1	0	0	1	0	0	0	1
	6. Point to share experience.	M	M	M	0	1	0	1	0	0	0	1	0
8	1. Same level, face-to-face.	3	0	0	3	0	0	1	1	0	0	0	1
	2. Avoid questions.	0	2	0	2	0	0	0	1	0	1	0	0
	3. Model language around child's focus.	3	0	0	2	9	0	2	1	1	1	6	14
	5. Use same words.	1	0	0	1	0	0	1	4	0	0	1	0
	6. Follow commands using ADL.	3	0	0	10	0	0	0	1	0	0	1	0
	7. Pause & wait.	2	1	0	3	0	0	1	0	0	0	6	0
	8. Appropriate prompt.	5	0	0	4	0	0	0	1	0	4	3	5
Sum		179	38	23	96	45	1	32	45	31	78	128	97
Total opportunities		240			142			108			303		
FA strategies %		75%			67%			30%			26%		
FA+PA		202			97			63			175		
FA+PA %		84			68			58			58		

#	Strategy	WE17			YR24			YU22		
		FA	**NA**	**PA**	**FA**	**NA**	**PA**	**FA**	**NA**	**PA**
1	1. Adjusting environment.	1	3	0	1	0	0	1	0	0
	2. What child's is attentive to.	3	3	1	1	0	0	1	0	0
	3. Same level, face-to-face.	1	0	0	1	0	0	1	0	0
	4. Follow child's lead.	2	3	1	1	1	0	0	2	0
	5. Imitating the child.	2	4	0	0	3	0	6	11	0
	6. Pause & wait.	1	3	2	12	1	3	22	0	0
2	1. Finding reciprocal activity.	3	1	2	3	0	0	3	0	1
	2. Keeping parent turn short.	2	4	1	3	0	0	4	0	0
	3. Pause & wait.	2	4	3	23	0	0	22	0	1
	4. Adding sound effect.	6	1	0	3	0	0	23	5	0
3	1. Double sets of toys.	1	2	0	1	3	0	1	1	0
	2. Same level, face to face.	1	0	1	4	0	0	1	0	0
	3. Appropriate prompt.	0	7	1	10	0	0	6	0	0
	4. Adding sound effect.	4	0	5	4	0	1	2	0	0
4	1. Choosing short activity.	1	0	0	2	0	0	3	0	0
	2. Apply goal using ADL.	1	0	0	M	M	M	M	M	M
	3. Using visual cue.	1	5	0	28	0	4	42	0	53
	4. Waiting for the child.	0	3	1	0	13	0	0	32	0
	5. Modelling with another chid.	M	M	M	M	M	M	M	M	M
5	1. Double sets of toys.	2	0	0	1	0	0	0	2	0
	2. Adding sound effect.	3	0	3	2	0	0	1	0	0
	3. Appropriate prompt.	0	4	1	1	0	0	2	1	0
	4. Reinforcing child's imitation.	4	1	0	1	1	0	1	0	0
6	1. Selecting preferred object.	2	0	0	2	0	0	1	0	0
	2. Creating opportunities.	1	1	2	3	0	2	5	0	0
	3. Same level, face-to-face.	1	0	0	2	0	0	1	0	0
	5. Pause & wait.	0	2	1	3	3	2	4	0	0
	6. Appropriate prompt.	2	0	1	2	0	0	5	0	0
	7. Increase distance.	M	M	M	M	M	M	M	M	M
7	1. Selecting preferred object.	1	0	0	2	0	0	1	0	0
	2. Creating opportunities.	0	2	0	1	0	1	1	0	1
	3. Teaching how to point.	0	0	1	1	0	0	1	0	0
	4. Appropriate prompt.	0	1	1	1	0	3	9	4	0
	5. Increase distance.	0	1	0	1	0	1	0	1	0
	6. Point to share experience.	0	1	0	0	1	0	0	1	0
8	1. Same level, face-to-face.	1	0	0	7	0	0	2	3	0
	2. Avoid questions.	1	0	0	7	0	0	5	0	0
	3. Model language around child's focus.	2	0	2	12	0	0	4	4	1
	5. Use same words.	1	0	0	6	0	0	2	1	2
	6. Follow commands using ADL.	M	M	M	6	0	0	4	1	0
	7. Pause & wait.	1	1	0	2	0	0	1	0	1
	8. Appropriate prompt.	1	0	0	3	0	0	3	0	0
Sum		56	59	30	163	31	17	191	76	60
Total opportunities		145			211			327		
FA strategies %		39%			77%			58%		
FA+PA		86			170			251		
FA+PA %		59			81			77		