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The Development and Evaluation of a Culturally Appropriate Home-based Intervention for Children with Autism Spectrum Disorders in the Kingdom of Saudi Arabia

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Abstract

The limited research regarding Autism Spectrum Disorders (ASD) within the Kingdom of Saudi Arabia (KSA) suggests a serious lack of understanding of the disorder, a scarcity of ASD services, and few trained professionals. In addition, there are few studies of evidence-based practices to support families of children with ASD which are culturally appropriate in KSA. Research on families' experiences raising children with ASD indicated an urgent need for professional support. Home-based interventions (HBIs) administered by parents of children with ASD effectively receive ASD services within the naturalised home environment. This project aimed to develop and evaluate a culturally appropriate HBI to support families and their children with ASD in KSA. Three studies were conducted to complete this project throughout three phases; 1) A systematic review of the literature regarding HBIs, particularly the supportive factors and barriers that may influence the implementation and outcomes of HBIs, phase one. The findings of the first phase of this project were used to inform the subsequent phases to develop and implement culturally appropriate parental training programmes for families of children with ASD in KSA. 2) Implementing and evaluating the effectiveness of online group-based educational training for families of children with ASD in Saudi Arabia, phase two. 3) Implementing and evaluating the effectiveness of HBI for families of children with ASD in KSA, phase three.

The quantitative and qualitative data were collected and analysed to understand if HBI increased families' ASD awareness and ability to implement ASD strategies to improve children's behavioural outcomes. The feasibility of providing a culturally appropriate HBI for families and their children with ASD showed significant improvement in the outcomes of participants. The findings demonstrated that HBI effectively provided needed services for

families and their children with ASD who live in limited-resourced areas such as KSA. Additionally, this research was conducted during the global pandemic Covid-19. Thus, HBI was a solution to provide needed services for families and their children with ASD in a home setting to overcome some of the experienced challenges. The limitations of the included studies and future research suggestions were discussed.

This is a thesis by publication, and the structure includes three manuscripts that each act as a chapter.

Keywords: home-based interventions, families, children with autism spectrum disorders, Kingdom of Saudi Arabia

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List of Publications Arising from This Thesis

This thesis is presented with a series of publications. I am the lead author in all publications. One publication has been published, and two are under review.

1. Alanazi, H., Smith, C. A., Morrison, C. A. (Under Review). A systematic review of supportive factors and barriers for the implementation of home-based intervention for individuals with autism spectrum disorders.
2. Alanazi, H., Smith, C. A., Alsharif, Sh. S. (Under Review). Online group-based educational training for female caregivers of children with autism spectrum disorders in the Kingdom of Saudi Arabia.
3. Alanazi, H., Alsharif, S. & Smith, C. A. (2022). A home-based intervention for children with autism spectrum disorder: Outcomes for Saudi Arabian families. *Issues in Educational Research*, *32*(3), 849-870. http://www.iier.org.au/iier32/alanazi.pdf

Thesis Structure

This thesis presents a series of three publications. Several additional sections have been written to clarify the connections between manuscripts.

The thesis structure is presented below.

Chapter 1: Introduction

The first section provides an overview of the negative impacts of ASD on families of children with autism and their unmet needs. In addition, this chapter discusses home-based intervention (HBI) as a solution to provide needed services for families and their children with autism in the Kingdom of Saudi Arabia. This chapter describes the procedures of developing HBI throughout three phases and the implementation throughout two stages.

Chapter 2: A Systematic Review of Supportive Factors and Barriers to the Implementation of Home-Based Interventions for Individuals with Autism Spectrum Disorders

This study systematically reviewed 43 studies of HBIs published in the previous decade from 2010 to 2020. The findings provide information about the supportive factors and barriers that influence the implementation and outcomes of HBIs.

Chapter 3: Autism Effects on Families and a Potential Solution in the Kingdom of Saudi Arabia

The literature review provides information about the experiences of families of children with ASD in the Kingdom of Saudi Arabia, such as their perspective of available ASD services, their level of ASD understanding, and their quality of life. This information and the Systematic Review (Chapter 2) were used to develop individualised HBIs based on the needs of the participant families of children with ASD in the Kingdom of Saudi Arabia.

Definitions

Autism Spectrum Disorders: Autism spectrum disorder (ASD) is a developmental disorder defined by diagnostic criteria, which include impairments in communication and social skills and restrictive, persistent, repetitive patterns of behaviour or interests which persist across the lifespan (American Psychiatric Association, 2013).

Applied Behaviour Analysis: An application of strategies based on behaviourist principles, a learning theory to shape new behaviours or change problematic behaviours through operant conditioning by reinforcement (Cooper et al., 2007).

Culturally Appropriate: Interventions must consider cultural factors of the family and community, such as ethnicity, language, class, values, and religion.

Home-Based Interventions: Home-based interventions (HBIs) are widely used in ASD research to describe programmes where therapists train parents to implement strategies to teach their children different skills (Bearss et al., 2015).

Saudi Female Caregivers: The participants of the HBI were all women (mothers) who are primary caregivers for children with ASD in KSA. Including only women was one of this study's criteria for cultural adaptation of the HBI.

Knowledge-Focused Support: It is a theoretical parental training programme consisting of three prongs: educational support, psychosocial support, and coordination of support (Bearss et al., 2015). To increase families of children with ASD awareness, reduce parental mental health issues, and empower them to advocate for their children’s appropriate services.

Skill-Focused Support: A practical training programme to improve parenting skills and self-efficacy to facilitate children with ASD's acquisition of social communication, self-care, and play skills.

Abbreviations

HBIs	Home-Based Interventions
ASD	Autism Spectrum Disorders
ABA	Applied Behaviour Analysis
KSA	Kingdom of Saudi Arabia

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Chapter 1

Introduction

Autism Spectrum Disorders (ASD) are a group of developmental disorders that manifest as communication and social skill impairments and repetitive and persistent behavioural patterns or interests (American Psychiatric Association, 2013). ASD has a heterogeneous nature regarding both symptoms and severity across individuals. An early discussion of ASD within the research literature was found in Leo Kanner's 1943 article: "*Autistic Disturbances of Affective Contact"*, which described 11 patients with unique neurodevelopmental symptoms. Kanner suggested that the condition was caused by intelligent, educated, and emotionally absent parents (Sterwald & Baker, 2019). Specifically, Kanner blamed mothers for causing ASD in their children. Other early ASD research mentioned factors such as assistive reproductive technology, maternal smoking, vaccinations, and thimerosal exposure (Modabbernia et al., 2017; Rutter, 2011).

Further, some connections were explored between ASD and the development and symptomology of childhood schizophrenia. Early treatments for ASD included electric shock and behaviour modification focusing on pain and punishment (Thompson, 2013; Wolff, 2004). This lack of understanding of the disorder and early research directions resulted in many misunderstandings regarding the ASD causes, symptoms, and effective interventions (Rutter, 2011). There are residual effects even today, one of which is that parents of children with ASD often suffer misdirected guilt because they believe they have done something to cause their children's disorder.

Advances in Research

Fortunately, research regarding ASD has advanced since those early years, improving ASD awareness and services in identification and interventions (Rice & Lee, 2017). Current evidence indicates that the factors regarding ASD causes previously raised are unrelated to ASD (Modabbernia et al., 2017; Thompson, 2013). Researchers have found several different genetic and environmental factors which may interact with each other in the development of ASD (Modabbernia et al., 2017; Thompson, 2013). Research into the causal factors for ASD is continuing, and some identified factors include advanced parental age, infections during pregnancy, birth complications, and toxic environmental elements, such as lead and mercury are likely to influence the risk of ASD (Modabbernia et al., 2017; Ratajczak, 2011). The World Health Organisation (WHO) managed and published two diagnostic manuals, including the International Classification of Disease (ICD) and the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), a well-respected, authoritative guides in use by mental and health professionals across the world to diagnose diseases and disorders. The ICD is a broad manual describing all diseases and disorders, while DSM-5 only describes mental health disorders. Therefore, DSM-5 is more accurate in diagnosing ASD, which outlined three categories for diagnosing individuals with ASD, including restricted and repetitive behaviours, impairments in social interaction, and communication deficits (American Psychiatric Association, 2013).

Because ASD is a behavioural disorder, there is no medical test to diagnose individuals with ASD (Dover & Le Couteur, 2007; Thompson, 2013). Professionals in the field of ASD have used the DSM-5 description, symptoms, and criteria for an ASD diagnosis to develop ASD diagnostic, screening, and assessment tools implemented through behavioural observations in clinical settings. Some examples of validated instruments include Childhood Autism Rating

Scale (CARS-2) (Schopler et al., 1980), the Autistic Diagnostic Observation Schedule (ADOS-G) (Lord et al., 2000), Gilliam Autism Rating Scale (GARS-2) (Karren, 2017), and Autism Diagnostic Interview (ADI-R) (Rutter et al., 2003). This standardisation of diagnostic assessments provides diagnosis accuracy for individuals with ASD. It makes it more likely that they will be able to receive more effective early interventions. Research shows that effective early interventions are critical for positive outcomes for children with ASD (Chang & Locke, 2016).

Applied Behavioural Analysis

Applied Behavioural Analysis (ABA) is a well-researched approach to teaching individuals with ASD in all developmental domains, leading to more significant outcomes in independent living (Frost et al., 2020; Rodgers et al., 2021). Through intensive behavioural interventions, ABA is an effective approach to support infants, youth, and adults with ASD (Granpeesheh et al., 2009), particularly to increase positive behaviours and reduce challenging behaviours targeted specifically to meet the needs of the child (Cooper et al., 2007). Systematically researched with clear scientific findings, there is demonstrated effectiveness for ABA interventions that significantly improve child outcomes in the areas of social communication (Blake et al., 2017), physical (Kato, 2018), self-care (Popovic, 2017), and play skills (Besler & Kurst, 2016), and reduces problematic behaviour in persons with ASD (Scahill et al., 2016). ABA research includes more than 45 years of developing evidence-based practices that help professionals understand and control behaviours' antecedents and consequences (Cooper et al., 2007). ABA is grounded in the learning principles developed by BF Skinner, who believed that behaviour is shaped by its consequences, including positive and negative reinforcement and punishment. Children with ASD learn essential life skills and a wide range of

academic skills through the systematic approach to teaching using the principles of ABA (Granpeesheh et al., 2009).

Problems Regarding Availability of Services

Research has provided a more accurate understanding of ASD, which has positively contributed to developing more effective methods to support the learning and development of individuals with ASD. However, in many areas of the world, there is still little support for families and inadequate services for their children with ASD, including diagnostic and therapeutic services (World Health Organization, 2019). Because of this, children lack the services they need to thrive (Bishop-Fitzpatrick & Kind, 2017; Nguyen et al., 2016; Pettygrove et al., 2013). Families from low socioeconomic status or remote areas often experience difficulties accessing appropriate services for their children with ASD (Dieleman et al., 2018; DeVries, 2016; Jafarabadi et al., 2021; Marsack-Topolewski & Weisz, 2020). This creates unequal access to quality services in different geographic locations, including a shortage of healthcare and educational providers, a lack of ASD awareness between professionals and the general public, and a shortage of culturally appropriate ASD diagnostic services and interventions (Hidalgo et al., 2015; Nguyen et al., 2016; Sim et al., 2017). Besides the shortage of services, this cultural inadequacy is a problem because it limits the ability to replicate successful research regarding evidence-based interventions with participants from diverse locations and cultures (Liaoa et al., 2017).

Impact of Lack of Services on Families and Children

Children with ASD are more likely to be misdiagnosed or untreated without access to knowledgeable professionals and appropriate services (Nguyen et al., 2016; Pruitt et al., 2016). This can delay young children's acquisition of foundational skills if they cannot receive

appropriate services and gain independent living skills, such as social communication and self-care. Further, without adequate support, children with ASD may experience an increase in the severity of symptoms. These problems are also likely to affect the families' mental health and well-being negatively, impacting their marriage and careers (Dieleman et al., 2018; Galpin et al., 2018). Despite the significant advances in research and practice to support children with ASD and their families' psychological and socioeconomic challenges, there are still challenges (Bearss et al., 2015; Leaf et al., 2018).

Home-Based Interventions as a Solution

Home-Based Interventions (HBIs) have been shown by research as an effective method for supporting families and their children with ASD in naturalistic environments (Bearss et al., 2015; Wakeford, 2017). A significant element of HBIs is parental training, which has been used to increase parental knowledge of ASD (Shire et al., 2016), support the parent-child relationship, and enhance parental self-efficacy to improve their children's developmental outcomes (Iadarola et al., 2018; Scahill et al., 2016). HBIs have been quantitatively and qualitatively measured, showing significant positive outcomes for parents and children with ASD (Frantz et al., 2017). HBIs are cost-effective, with a high level of parent satisfaction and acceptability (Connolly, 2015), and effective in overcoming transportation issues through online services, which increase access in limited-resources areas (Pickard et al., 2016). Research indicated that HBIs could help to disseminate ASD services to support families and their children with ASD who experience difficulties accessing and receiving ASD services (Blake et al., 2017; Connolly, 2015). Parental training programmes to implement ASD interventions in home settings can be a solution to address the needs of children with ASD who live in limited resource settings.

A Culturally Appropriate Home-Based Intervention

Culture impacts ASD interventions in terms of targets, behavioural, and quality of services (Liaoa et al., 2017). The reapplication of HBIs across cultures should be adapted to fit a specific culture's context (Liaoa et al., 2017). The development and implementation of ASD interventions should be culturally appropriate to respect cultural norms regarding language, religion beliefs systems, social behaviours, traditional customs, and ethical values. Therefore, showing an awareness of and respect for cultural and religious practices in developing and implementing HBIs is important in Saudi Arabian culture. For example, the Saudi Arabian culture stems from the constitution of the Holy Quran and follows Islamic law (Sharia), which defines acceptable ways for individuals to think and behave. This heavily influences the educational policy and practices across KSA, including establishing educational policy, rules, and quality of learning standards for children. In Saudi Arabian culture, it is important to use traditional food, clothes, and the child's native language when developing the intervention. In addition, the Islamic community requires gender segregation; therefore, the implementation of HBIs in home-settings should be by the same gender. Further, videotaping as a data collection method or sharing pictures would not be appropriate because Muslim women wear Hijabs. Considering these variables in developing and implementing HBIs allows families and their children with ASD in KSA to take advantage of HBIs.

Although there are advantages, more information is needed because participant benefits vary across studies for families and children with ASD (MacKenzie & Eack, 2022; Shalev et al., 2019). HBIs involve various components, including the intervention design, method of delivery, and individual procedures. Further, the individual characteristics of the participants, interventionists, and the intervention duration are important variables that may contribute to

supportive factors or barriers, depending on the situation. More information is needed to better understand how these variables interact and influence the outcomes of the HBIs to provide professionals with sufficient knowledge to develop and implement effective HBIs that address individual families' needs (MacKenzie & Eack, 2022; Shalev et al., 2019).

This project aimed to develop and evaluate a culturally appropriate HBI for families and their children with ASD in KSA. This project was conducted across three phases. The results were disseminated through three publications in peer-reviewed journals to report the development of culturally appropriate HBIs to support families and their children with ASD. The first phase included conducting a systematic review of the literature related to relevant supportive factors and barriers of HBIs and is presented as publication 1 in Chapter 2. Next, a targeted literature review was conducted to identify the experiences of families in KSA with children with ASD, which is presented in Chapter 3. Finally, Chapters 4 and 5 present the information gained through these two literature reviews used to develop individualised, culturally appropriate HBIs to support families and their children with ASD in KSA.

The first stage consisted of a theoretical training programme to implement and evaluate the effectiveness of online group-based educational training for families of children with ASD in KSA (Chapter 4). The second stage consisted of a practical training programme to implement and evaluate the effectiveness of HBI for families of children with ASD in KSA (Chapter 4). See Figure 1 for a graphic description of the studies.

My Position in the Research

Before starting my PhD, I worked as a specialist for children with ASD in KSA. I often witnessed practices Saudi families use that can be detrimental to their children's health and behaviour rather than helpful. For example, some families use non-prescription medicines to

treat their children's disorders which can be harmful. Further, families received conflicting information from various resources, including unofficial sources, such as websites, social media, or the experiences of other families and friends. With often receiving misinformation, they were more likely to come up with their interpretations and may construct their intervention context. There are a lot of complex and interconnecting cultural and environmental variables that influence their decisions. I wanted to work towards changing families' perceptions regarding teaching their children with ASD using culturally appropriate evidence-based interventions.

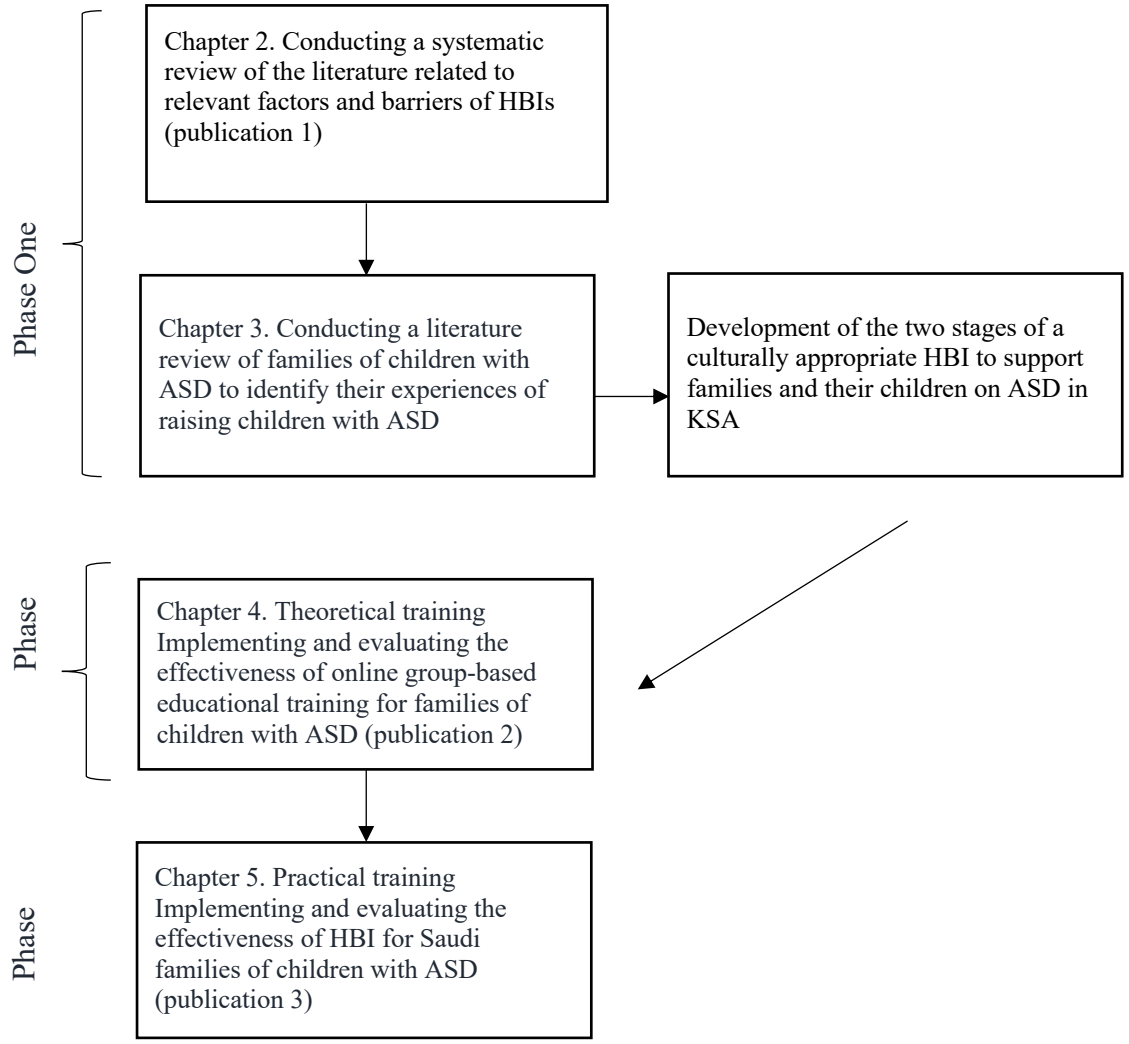
The Purpose of the Study

The shortage of culturally appropriate ASD interventions to support families and their children with ASD from different cultures is seen worldwide. This requires researchers and professionals in the ASD field to address cultural diversity in their practices. Therefore, to fill the gap in research, limited evidence-based interventions are conducted in the Saudi community to support families and their children with ASD. The study aimed to develop and evaluate the effectiveness of a culturally appropriate HBI in increasing families' ASD awareness and self-efficacy to implement strategies to address the needs of their children with ASD. Therefore, an individualised HBI was developed and implemented to contribute to the evidence-based practices that support families of children with ASD in KSA. First, a systematic review of the research literature was conducted to identify supportive factors and barriers associated with the implementation and outcomes of HBIs. Subsequently, an HBI appropriate for the Saudi context was developed using the information gathered from the systematic review. All the HBI contents, including materials, selected behavioural goals, and assessments, were linguistically and culturally responsive. Then, the first stage of the parental training programme was delivered to increase Saudi mothers' ASD awareness, and the pre and post-test surveys were implemented.

The second stage of the parental training programme was also provided, including training mothers and collecting data. All authors analysed the data of these two parental training programme stages.

Figure 1

The Phases of the Development and Evaluation of the HBI Project



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Chapter 2

A Systematic Review of Supportive Factors and Barriers for the Implementation of Home-Based Interventions for Individuals with Autism Spectrum Disorders

Preface

This study systematically reviewed research literature investigating the use of Home-Based Interventions (HBIs). This study aimed to identify factors that influence the implementation and outcomes of HBIs. The findings supported the development of culturally appropriate HBI for families and their children with ASD in KSA. This study informed the subsequent phases of this project, including the intervention's content and data collection methods, the second publication (Chapter 4), and the third publication (Chapter 5).

The manuscript was submitted for consideration to a peer-reviewed research journal and is currently under review.

Abstract

Home-Based Interventions (HBIs) are a well-documented support method for children with Autism Spectrum Disorders. However, the research presents limited information regarding factors that may influence the implementation and outcomes of HBIs. Forty-three studies published in the previous decade, from 2010 to 2020, were systematically reviewed, and findings were extracted to better understand factors influencing the implementation and outcomes of HBIs. Studies varied as to research designs, type of interventions, duration, and country of origin. Results indicated several supportive factors and barriers, including intervention and environmental characteristics as well as characteristics of participants and interventionists. Implications for future research and limitations of the study are discussed.

Keywords: home-based interventions, parent-mediated interventions, parent-implemented interventions, parent-centred interventions, parents coaching, parent training, autism

A Systematic Review of Supportive Factors and Barriers for the Implementation of Home-Based Interventions for Individuals with Autism Spectrum Disorders

Autism spectrum disorders (ASD) are a group of developmental disorders defined by diagnostic criteria, including impairments in communication and social skills and restrictive, persistent, repetitive patterns of behaviour or interests which are pervasive across the lifespan and interfere with independent living skills (American Psychiatric Association, 2013). Parents of a child with ASD often experience emotional, physical, and financial challenges resulting in relationship stress and overall negative effects on family functioning and well-being (Dieleman et al., 2018; Sim et al., 2017). In the past decade, there has been an increase in the quality and quantity of research within the field that aimed at gaining a better understanding of the aetiology and symptomatology of ASD and developing interventions to support individuals with ASD and their parents. One method of providing effective support for children with ASD and the needs of their parents is through interventions administered within the home by the child's parents (Leaf et al., 2018). Because children generally spend a lot of time with their parents, training parents to deliver interventions for their children can effectively provide early intervention and support. However, these interventions must be evidence-based, effective, socially valid, and sustainable within the context of the family setting (Shalev et al., 2019).

Home-based interventions (HBIs) are widely used in ASD research to describe programmes in which therapists train parents (Bearss et al., 2015) and include a broad set of intervention types and a variety of delivery formats, duration, and targeted ages. Targeted interventions may address specific ASD symptomatology, including difficulty with social communication and restricted and repetitive behaviour patterns or functional behaviours such as self-care, social interaction, and academic skills. Parents can be trained to administer HBIs face

to face or using online web-based technologies. The training and support may range from two weeks to several years, with the intervention delivered after training by a child's caregiver, including a parent or other family members who are in the home (Bearss et al., 2015). HBIs may be developed to support individuals with ASD across the lifespan, including infants, children, and adults. This method focuses on supporting the needs of the individual with ASD or that of the individual as well as their parent or family member, such as psychoeducational training to provide accurate information, support stress reduction and coordinate community support (e.g., social groups and financial support) (Bearss et al., 2015).

Findings from the current literature indicate that HBIs are an effective method for delivering different types of interventions to parents and children with various needs and characteristics (Bearess et al., 2015; Leaf et al., 2018). For example, there are many advantages of HBIs, including an increase in parental involvement with the child's treatment (Leaf et al., 2017), such as increased cost-effectiveness for the parents, as well as eliminating barriers such as transportation issues and scarcity of available services (Little et al., 2018). Existing research is clear that HBIs can be an effective way to support both parents and their children with ASD. However, effect sizes vary across studies. More information is needed to understand what specific factors impact positive outcomes for specific groups of participants (MacKenzie & Eack, 2022; Oono et al., 2013). There is some evidence around specific factors that may positively impact the successful implementation of HBIs to promote positive outcomes and barriers to success. The specific characteristics of the family may contribute significantly to child outcomes (Shalev et al., 2019). For instance, lower stress levels of parents were associated with significant improvements in children's treatment outcomes. Further, parental training was not likely to be effective without the trainer's ongoing practical training and support to implement

the strategies and interventions they learned (Bearss et al., 2015). In addition, a systematic review conducted by Mackenzie and Eack (2022) regarding the effectiveness of HBIs for parents found no improvement in mental health, parenting burden, and family adjustment.

Research Gap

Although there is a large body of research regarding the use of HBIs to support parents with children with ASD, as previously mentioned, it is unclear what specific characteristics may influence HBIs outcomes. It is important to investigate this gap in the research to better understand the specific factors which may influence the outcomes of the HBIs, including their purpose, delivery, and design of the interventions. This would help better understand the effective design and delivery of HBIs to be effective and appropriate for participants' diversities and needs. Therefore, this systematic review aimed to clarify HBIs, including appropriately developed effective, valid, and culturally relevant programmes to support parents and children with ASD.

An early systematic review conducted by McConachie and colleagues (2007) concluded that parental training for interventions could be an important support method for children with ASD and their parents. However, the review found that this area's research often lacked the rigour for effective evaluation. In addition, the review highlighted the importance of a holistic approach to ongoing parental support. More recent research literature has sought to measure the effectiveness of HBIs across different types of interventions and parents' ability to implement HBIs with fidelity to support the needs of individuals with ASD as well as their parents. This research is necessarily broad in scope because of the complexity of the interventions and the characteristics of both the children and their parents, which may impact outcomes (Salomone & Arduino, 2017; Shalev et al., 2019). There is a need to better understand the effective elements of

HBIs so that practitioners can develop specific programmes for children with ASD and the parents with which they work. Therefore, the purpose of the current study is to conduct a systematic review of relevant published research on this subject since the work of McConachie et al. (2007) is to understand the specific elements of HBIs that are essential to consider for effective, sustainable child and parental support. This systematic review is intentionally limited in scope, focusing on using HBI to support parents in effectively delivering early intervention support for their children with ASD within the home.

Methodology of Studies

In the previous systematic review conducted by McConachie and colleagues (2007), only studies using randomised controlled trials (RCT) were analysed. In their seminal work, Odem et al. (2005) thoroughly addressed this issue concerning the context of research, specifically within the field of special education. A carefully conducted RCT will provide important information as to quality interventions for instruction and interventions; however, the complexity and individualistic nature of special education requires that researchers look beyond this single methodology and consider methodologies more appropriate to specific research questions. Therefore, this review carefully considered studies using various methodologies, including RCT, quasi-experimental, single-subject design, and qualitative studies, specifically considering each study's context, specific research questions, validity, and efficacy. This holistic examination of the research is essential to address the significant gap in this area of research. It is imperative to implement methodologies to explore the variables associated with HBIs implementation and outcomes, including the intervention, caregiver training, within-person caregiver characteristics, home environment, and culture. These findings are vital to providing crucial information for high-quality, effective training programmes to support caregivers and provide effective

interventions for children with ASD. A clear understanding of the various individual variables which affect implementation will allow adjustments to support the participants while maintaining the quality of the HBIs and therefore support intended positive child outcomes.

Methods

Inclusion Criteria

Included studies were determined by these specific criteria: (a) studies were published in English; (b) published in a peer-reviewed scholarly journal or as a completed dissertation or thesis; (c) were published between 2010 to 2020; (d) included an intervention, which provided parental education training, practical training or both; (f) the intervention was delivered by parents, not outside professionals or other caregivers; (e) the intervention consisted of a minimum duration of two weeks; (g) the study included an intervention for children with a diagnosis of ASD; (h) the target age of children was from 3 to 12 years; (i) the included intervention was conducted within the participants' home; (j) the study assessed social fidelity. Studies that did not meet these criteria were excluded.

Information Sources and Search

Articles were thoughtfully screened and included according to the PRISMA guidelines for a systematic review (Moher et al., 2010). First, the research studies were identified through string searches in the databases: ProQuest, ERIC, and PsycINFO using the search terms: parent coaching, educating parents, parent training, parent support, parent-centred, parent-implemented, parent-mediated, promoting parent engagement, home-based intervention, children with autism. This initial screening resulted in 81 studies meeting the inclusion criteria. There were multiple determination points to assess if each study should be included. See Figure 1 for a graphic representation of this process.

First, all of the studies were entered into an Excel spreadsheet. Two reviewers were asked to read the title and abstract of each study, considering the inclusion criteria, and recommend as: include, do not include, or not sure. The reviewers met to consider any studies marked differently and discussed until a consensus was reached. This process resulted in 61 of the 81 studies being retained. Next, the reviewers conducted a full-text review of the 61 retained studies. Again, they entered their recommendations into the Excel spreadsheet as: include, do not include, or not sure, including notes on their rationale or the determination. The reviewers again met and discussed any recommendations that differed until a consensus was reached. Disagreements were discussed and resolved with a third reviewer, including the notes on inclusion or exclusion, to establish further validity of the selection process, and concurred with the rationale provided, who confirmed subsequent results. As a result of this process, 42 of the 61 studies were retained. Finally, because of the time that passed between the original search and the completion of the project, a subsequent search was conducted in early 2022, resulting in the identification of one additional article published in September 2020 after the original search. After completing the above steps, it was determined that this additional article met the criteria and was included in the final count of 43 articles subjected to a full-text review, as described in the following section. It is important to note that no studies were excluded because of reported HBI effectiveness. However, the study design, types of intervention, and efficacy were noted and categorised.

Data Extraction and Evaluation

Following the identification of articles to be included, a coding guide was developed to effectively extract and categorise the information from the studies regarding specific supportive factors or barriers to implementing HBIs. This process, including the determination of data to be extracted, was completed by two reviewers (first and second authors), who also have extensive

experience in the support and education of individuals with ASD as well as parental support. The coding guide identified specific categories, including purpose and method of intervention delivery, intervention design, format, and intervention outcomes. Also categorised were factors of HBI implementation, including adaptations made to the content and implementation procedures (including reasons) and identified barriers to implementation. Next, participant characteristics that might influence implementation and outcomes are identified, such as the severity of child symptoms, including disruptive behaviour, family socioeconomic status, and characteristics of the interventionists who trained the parents. Finally, qualitative data from social fidelity assessments of the reviewed studies was gathered to understand the families' perspectives effectively.

The first author developed the coding guide with ongoing collaboration between the first and second authors. After the initial data entry was completed by the first author and reviewed by the second author, collaborative discussions ensued with the third author to ensure clarity and resolve any disagreements, who then reviewed the data as a validity check. The data indicated several supportive factors and barriers that influence implementation and outcomes, including intervention and environmental characteristics and characteristics of the family and interventionists. A full discussion of the results is provided in the following section.

Results

After eliminating duplicates, the search yielded 81 research journal articles, dissertations, and theses. The reviewers independently screened the article abstracts to determine whether the inclusion criteria were met. After discussion and further review, 43 articles remained the basis of the systematic review and were subjected to the review process as previously described.

Geographic Locations

The majority of the studies (n=36) were conducted in Western countries, including the United States of America (n=29), Canada (n=4), and the United Kingdom (n=2). One study was conducted in South Africa, and the rest in various Middle Eastern countries, including India (n=3), Turkey (n=1), Bangladesh (n=1), and Saudi Arabia (n= 1). There was an overall upward publication trend: from 2010 to 2015, only 14 studies were published. However, the number of studies published from 2016-2020 more than doubled (n=29). The majority of the articles (n= 25) were published in peer-reviewed journals, with the remainder consisting of the published doctoral thesis (n=13) and master thesis (n=5). The studies used different research designs to measure HBI outcomes, including single subject design (n=22), quasi-experimental (n=1), experimental (n=5), randomised controlled trial (n=7), qualitative (n=3), and case study (n=4). Further, studies varied regarding the purpose and reported findings, including participant outcomes and intervention strategy effectiveness differed across the reviewed studies. The reviewers conducted an in-depth review of the studies to extract the findings. They categorised the information into four general domains, including intervention characteristics, environmental characteristics (i.e., culture and geography), participants' characteristics (i.e., parent and child), and interventionists' characteristics (i.e., competency or level of support). A discussion of these findings is presented in the following sections. See Table 1 for more specific information on the four domains' findings.

Intervention and Environmental Characteristics

Intervention Characteristics

HBIs discussed in the reviewed studies include both types of parental support: knowledge-focused and skill-focused support. Knowledge-focused support includes three areas

of parental support: 1) educational training, which focuses on increasing parents' ASD awareness and adjusting their expectations for their children's disorder; 2) psychological support, which seeks to help parents develop coping strategies to reduce the level of depression and stress and enhance emotional regulation, and 3) coordination across medical, social and school-based services to enable effective parental advocacy for their children to access appropriate services. Skill-focused support involves training to support the parental implementation of behavioural strategies and enhance the parents' self-efficacy.

Overall, there is a strong focus on developing parents' ability to understand ASD and implement behavioural management strategies with little consideration of their mental health and well-being needs. For instance, most of the studies (n=27) provided only skill-focused support, and an additional 13 studies provided both educational training and skill-focused support. In contrast, only 2 studies provided psychological support, and only one study provided support for parents to understand coordination across services. Furthermore, some studies (n=8) have sought to measure parental stress as an additional outcome of implementing HBIs. However, the findings of these studies have not shown a reduction of parental stress because the content of HBIs did not include psychological support to reduce parental mental health issues. Consistent with Mackenzie and Eack's (2022) findings, not addressing specific parental needs, including stress, could act as a barrier and prevent significant changes in parental mental health outcomes.

Environmental Characteristics

The reviewed studies provided evidence that specific environmental characteristics which support the effective delivery of HBIs can be critical to support positive child and parent outcomes. These characteristics may include the adaption of delivery methods, the duration or content of the HBIs to enhance the contextual fit for the family in terms of culture, geography,

and available family resources (Alnemary, 2017; Bishop-Fitzpatrick et al., 2017; Nguyen et al., 2016; Pettygrove et al., 2013). Research is clear that these factors may affect the outcomes of parents and their children, including their ability to access services as well as service quality. The reviewed studies found a positive relationship between HBIs specifically developed to consider the family's needs and characteristics and the level of parent acceptability, satisfaction, and implementation fidelity. Evidence shows that delivering the foundational, theoretical portions of HBIs within a group-based format provides parents with additional peer and social support (O'Donovan et al., 2019). According to this review, five studies provided knowledge-focused support (educational training) for parents of children with ASD in group-based settings. The social fidelity assessments provided information about parent satisfaction as a result of opportunities to share their experiences with subsequent improved engagement levels. Thus, group-based training was a supportive factor in enhancing parents' outcomes and improving parents' ASD-related knowledge.

Culture

As mentioned previously, most HBIs have been developed within a Western societal context, limiting the generalisation of the findings across cultures (Kelly et al., 2016; Liao et al., 2018). Cultural differences may significantly influence the ability to replicate HBIs. An HBI needs to be able to provide strategies for teaching culturally meaningful behaviours and be practical for families (Liao et al., 2018). Six reviewed studies adapted HBIs to be culturally appropriate for parents while preserving the active components of the HBIs and maintaining a high level of fidelity. Social validity data across the studies demonstrated that parents could be taught strategies to support the development of culturally appropriate child behaviours. Overall,

cultural adaptations of HBIs were supportive factors in improving parent and child outcomes and increasing access to evidence-based practices such as HBIs developed in Western settings.

Twenty-one studies adapted the HBIs content to consider the family's functionality, for instance, including the parents as collaborative partners to develop individualised plans and consider family routines and the parent priorities in goal development. The findings of these studies indicated that parents tended to be more willing to comply with the HBIs process. Moreover, their feelings of empowerment, motivation, and commitment increased when these adaptations were present. In addition, the parents reported embedding teaching strategies for their children within their daily routines. This increased the frequency and intensity of exposure to HBIs and resulted in more opportunities to practice without setting aside specific practice times (Araya, 2018; Blake et al., 2017; Oliver, 2018; Prelock et al., 2011). Individualised family planning and active family collaboration can support positive outcomes while respecting individual family lifestyles, values, and autonomy (Shalev et al., 2015; Zuckerman et al., 2016).

Geography

Because available ASD services vary across countries, with large disparities found even within countries across urban or rural areas, it is vital to find alternate methods of providing supportive services so that all families have sufficient access (Jafarabadi et al., 2021). One method of supporting families in low-resource areas is through web-based technologies. Close to one-fourth of the reviewed studies (n=10) adapted the HBIs to utilise long-distance training to provide evidence-based interventions through web-based technologies, including telephone/telehealth, email, and video conferencing (Table 1). According to parent reports, these remote services were cost-effective, helped to manage transportation issues and allowed access to additional ASD services, and increased engagement in their child’s treatment (Boutain, 2014;

Connolly, 2015; Little et al., 2018; McGarry et al., 2019; Meadan et al., 2013; Nicksic-Springer, 2016; Salomone & Arduino, 2017; Tran, 2018; Wainer & Ingersoll, 2015). Although these methods allowed flexibility in scheduling and access to HBI content, training, and support, some barriers related to long-distance training should be considered for HBIs. These barriers were associated with parent characteristics and are discussed in the following section.

Participant and Interventionist Characteristics

Participants Characteristics

The participants' specific characteristics and circumstances can influence HBIs and are very important to consider when making decisions regarding the content and delivery to achieve positive outcomes (Alquraini et al., 2018; Shalev et al., 2019). There is evidence of a positive relationship between higher levels of parental education and income and lower parental age with successful HBIs implementation (Besler & Kurt, 2016; Carr & Lord, 2016; Gwin, 2018). However, eight studies considered the lower socioeconomic status of the families to be a barrier to long-distance HBI training. Parents with fewer resources and those who live in remote areas reported struggling with online HBI training and implementation because of a lack of appropriate devices and internet service availability. Further, some studies (n=7) reported difficulties with long-distance training due to a lack of technology skills resulting in less positive child outcomes or even withdrawal from the programme. When planning an HBI, the interventionist needs to understand the level of support likely for the parents and plan the most effective method to provide the support. Additional tutorials may be required to use technology devices and programmes, as well as ongoing interventionist support, which may mitigate some of these barriers.

Lower levels of parental education and literacy were noted in five studies as a barrier to understanding HBI content, as well as negatively impacting implementation fidelity and engagement. This barrier can be lowered by adopting written materials with simpler vocabulary and conducting the training in shorter, simpler, more frequent lessons (Bradshaw et al., 2017; Shire et al., 2016). Furthermore, familial circumstances such as busy schedules, family illness, or marital issues were noted as barriers in 13 studies resulting in missed HBI training and implementation sessions and negatively influencing implementation fidelity. However, higher interventionist support can mitigate these barriers and allow all parents to achieve positive outcomes through HBIs. This increased support might include flexibility in scheduling and cancellation policies to support families as needed to overcome unforeseen familial circumstances and challenges.

Child characteristics, such as the level of cognitive functioning, severity, and manner of manifestation of ASD symptoms, are crucial factors that impact child outcomes overall (Bradshaw et al., 2017; Kuravackel et al., 2018; Padmanabha et al., 2019). Findings from (n=5) studies found no significant improvements for children with more severe ASD symptoms in short-term HBI. In addition, two reviewed studies found that a higher level of child disruptive behaviours negatively influenced HBI outcomes (Shindorf, 2019; Taylor, 2014). Accordingly, children's level of ASD severity and disruptive behaviours must be considered carefully in developing an individual HBI, considering the unique situation for each child and family. Therefore, it is not appropriate to name an estimated period or level of support that is appropriate for all children to reach positive outcomes. Rather interventionists must focus on the particular situation and characteristics of each family.

Interventionists Characteristics

Positive parent and child outcomes through HBIs are highly dependent on an effective transfer of information and support by the interventionist delivering the training and support. This delivery must be professional, culturally competent, and sensitive to the family's needs with adequate flexibility (Araya, 2018; Kirby, 2012). These important characteristics are discussed in detail in the following section.

Competency

Appropriate levels of qualification and the interventionist experience were noted across studies as supportive factors for the successful implementation of HBIs (Carr & Lord, 2016; Kirby, 2012; Kuravackel et al., 2018; Pickard, et al., 2016; Salomone & Arduino, 2017; Turner-Brown et al., 2019; Vaughn, 2012). In ten of the reviewed studies, parent reports indicated that they believed their experience was positively enhanced and supported their learning, engagement, and sense of empowerment if the interventionists displayed appropriate levels of cultural competence, were supportive, flexible, and willing to problem solve through consultation (Araya, 2018; Kato, 2018; Kirby, 2012; Pickard et al., 2016; Raj & Salagame, 2010; Ramseur, 2018; Shindorf, 2019; Tran, 2018; Vivian et al., 2012; Wakeford, 2017). Evidence showed that these factors supported higher levels of parent motivation, adherence, and HBI completion.

Level of Support

Parents noted ongoing communication with the interventionists as a crucial supportive factor. For example, parents who received an email and text reminders were likelier to complete the HBIs procedures (Connolly, 2015; Kato, 2018; McGarry et al., 2019; Nicksic-Springer, 2016; Suppo & Mayton, 2014). Continual, open communication allowed an effective method to

identify challenges and address misunderstandings. Providing immediate oral and written performance-based feedback helped address the parents' concerns, feelings, and problems. A variety of coaching and teaching methods to support parents across a broad range of education and literacy levels were identified as effective, including modelling, multiple opportunities for practice and role play, and provision of video examples (Al-zayer, 2014; Araya, 2018; Blake et al., 2017; Bradshaw et al., 2017; Carr & Lord, 2016; Connolly, 2015).

Discussion

This systematic review aimed to better understand the specific characteristics of HBIs used to support children with ASD and their parents and may influence outcomes. Children with ASD often have complex needs and require comprehensive services and care coordination across educational and medical systems (Karst & Van Hecke, 2012; Shahidullah et al., 2018). Therefore, holistic support of parents and their children with ASD through HBIs may be useful. However, identifying specific factors to support outcomes and barriers is critical (Bearess et al., 2015; Karst & Van Hecke, 2012; Leaf et al., 2018). Overall, this review found clear evidence that HBIs can be effective when adapted through collaboration with the family to consider the family's cultural needs, lifestyle, and particular characteristics. Further, it is essential to provide the family with effective and ongoing professional support (Ennis-Cole et al., 2013).

Evidence-based, developmentally appropriate HBIs implemented in the naturalistic home setting concerning the culture and needs of the family can be used to address the behavioural needs of children with ASD and increase the likelihood of positive developmental and behavioural outcomes (Karst & Van Hecke, 2012; Shahidullah et al., 2018). Effective support for parents must be ongoing and include both psychoeducation and skill-based content, with multiple avenues of support to provide parents with the needed skills to implement effective

interventions and improve child outcomes. Further, HBIs can provide an efficient and cost-effective support method for families in remote or rural areas (Connolly, 2015; Meadan et al., 2013).

Families of children with ASD have complex needs. The reviewed studies examined HBIs to address child skills across a wide domain, including challenging behaviours and social and communication skills (Blake et al., 2017; Phosaly, 2017; Popovic, 2017; Ramseur, 2018). Further, the parents benefited from HBIs, including increased ASD-related knowledge and therapeutic skills. With careful consideration, HBIs can provide comprehensive support for a family across different areas. Besides providing parents with the means to improve behavioural, social, and communication outcomes for their children with ASD, parent needs can also be addressed. To be most effective, an HBI must be specifically structured considering the family's unique characteristics, including their available resources, culture, and lifestyle, as well as the child's level of functioning with modifications made in terms of the content, duration, and methods of delivery and level of support.

Future Research

This review provides more clarity as to the available research in this important area. It highlights knowledge gaps, including understanding the best ways to support parents and their children with ASD. Future research should focus on effective components of HBIs which improve child outcomes while remaining sensitive to the needs of the family (Liao et al., 2018). Parenting children with ASD is a complex undertaking, and parents who do not have appropriate support are often socially isolated and financially stressed, with negative mental health impacts (Dieleman et al., 2018). Therefore, HBI programmes that provide holistic family support in these different areas could reduce parental stress and improve self-efficacy and parents' overall well-

being (Alquraini et al., 2018; Carr & Lord, 2016; Iadarola et al., 2018). Additional research on the efficacy of training and support for parents around such coping strategies as mindfulness-based intervention, relaxation strategies, and stress reduction techniques could be significant (Rayan & Ahmad, 2017). Further, more information to understand if parents may benefit from social and peer support through parenting groups in which they can connect and share similar experiences would be valuable. Overall, researchers and professionals who work with parents of children with ASD must keep in mind that they are parents and not professionals, and the most effective HBI services will always recognise and support their needs.

Figure 2

Inclusion and Exclusion Decision-Making Process Following PRISMA Guidelines

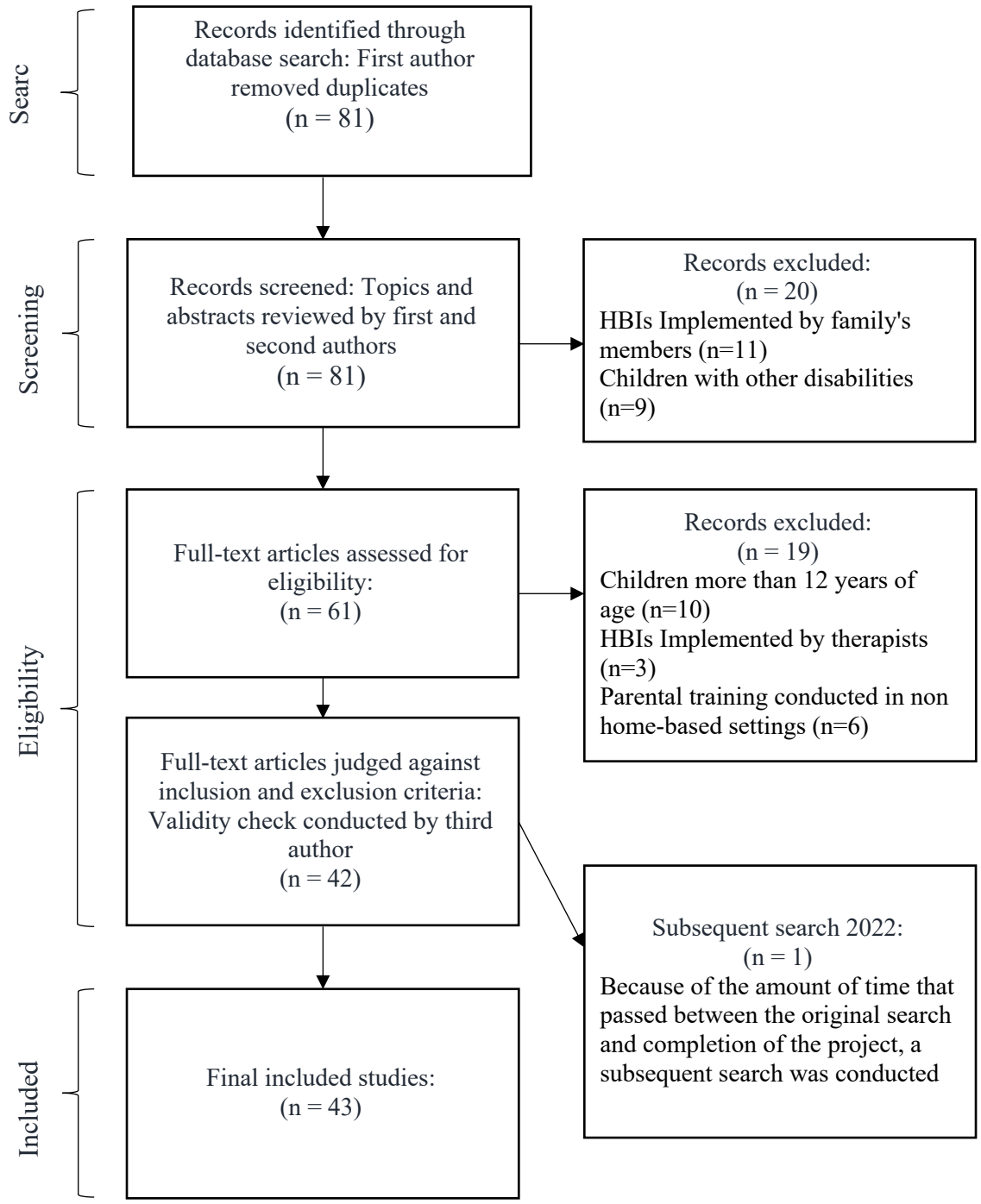

Table 1

Supportive Factors and Barriers Related to the Implementation and Outcomes of HBIs

Study	Interventions' characteristics				Environmental characteristics			Participants' characteristics			Interventionists' characteristics		Significant
	Knowledge-focused support	Skill-focused support	Psychological support	Coordination support	Adaption HBIs to be culturally appropriate	Adaption HBIs to be delivered online	Educational support in a group-based format	Parents' socioeconomic status	Family's issues	Severity of children's ASD symptoms	Competency	Level of support	
Alquraini et al. (2018)	-	Yes	-	-	SF	-		SF (high socioeconomic status)	-	-	-	-	Yes
Al-zayer (2014)	-	Yes	-	-	SF	-		-	-	-	-	SF	Yes
Araya (2018)	-	Yes	-	-	SF	-		-	-	-	SF	SF	Yes
Besler & Kurt (2016)		Yes	-	-	SF	-		SF (high socioeconomic status)	-	-	-	-	Yes
Blake et al. (2017)	-	Yes	-	-	SF	-	SF	-	-	-	SF	SF	Yes
Boutain (2014)	-	Yes	-	-	-	SF		-	-	-	SF	SF	Yes
Bradshaw et al. (2017)	-	Yes	-	-	-	-		-	-	SF (low ASD severity)	-	-	Yes
Carr & Lord (2016)	Yes	Yes	-	-	SF			SF			SF	SF	Yes
Connolly (2015)	-	Yes	-	-	-	SF	SF	-	-	-	SF	SF	Yes
Gwin (2018)	-	Yes	-	-	-	-	-	SF (high socioeconomic status)	BR (busy schedule and marital problems)	-	-	-	Mixed
Kato (2018)	-	Yes	-	-	SF	-	-	-	-	BR (disruptive behaviours)	SF	-	Mixed
Kirby (2012)	-	Yes	-	-	-	-	-	-	-	-	SF	SF	Yes
Kuravackel et al. (2018)	Yes	Yes	-	-	-	-	SF	SF (high socioeconomic status)	-	SF (low ASD severity)	SF	SF	Yes
Little et al. (2018)	Yes	Yes	-	-	-	SF	-	-	-	-	-	-	Yes
Manohar et al. (2019)	Yes	Yes	-	-	-	-	-	SF (high socioeconomic status)	-	-	-	-	Yes
McGarry et al. (2019)	Yes	Yes	-	-	SF	-	-	BR (low socioeconomic status)	-	-	-	-	Mixed

Study	Interventions' characteristics				Environmental characteristics			Participants' characteristics			Interventionists' characteristics		Significant
	Knowledge-focused support	Skill-focused support	Psychological support	Coordination support	Adaption HBIs to be culturally appropriate	Adaption HBIs to be delivered online	Educational support in a group-based format	Parents' socioeconomic status	Family's issues	Severity of children's ASD symptoms	Competency	Level of support	
Meadan et al. (2013)	-	Yes	-	-	-	SF	-	BR (low socioeconomic status)	-	-	-	-	Mixed
Mueller & Moskowitz (2020)	Yes	Yes	-	-	-	-	-	-	-	-	-	SF	Mixed
Nicksic-Springer (2016)	-	Yes	-	-	-	SF	-	BR (low socioeconomic status)	-	-	SF	SF	Mixed
Oliver (2018)	Yes	Yes	Yes	-	-	-	SF	-	-	-	-	SF	Yes
Padmanabha et al., 2019	-	Yes	-	-	SF	-	-	-	-	-	-	SF	Mixed
Phosaly (2017)	-	Yes	-	-	-	-	-	-	BR (marital problems and parent illness)	BR (high ASD severity)	-	-	Mixed
Pickard et al. (2016)	-	Yes	-	-	-	-	-	BR (low socioeconomic status)	-	-	-	-	Mixed
Pickard et al. (2016)	Yes	Yes	-	-	-	-	-	BR (low socioeconomic status)	-	-	-	SF	Mixed
Popovic (2017)	-	Yes	-	-	SF	-	-	BR (low socioeconomic status)	-	BR (high ASD severity)	-	SF	Mixed
Prelock et al. (2011)	-	Yes	-	-	SF	-	-	-	-	-	SF	SF	Yes
Raj & Salagame (2010)	Yes	Yes	-	-	-	-	-	-	-	-	SF	SF	Yes
Ramseur (2018)	-	Yes	-	-	SF	-	-	BR (low socioeconomic status)	-	-	-	SF	Mixed
Russell (2013)	-	Yes	-	-	-	-	-	-	-	BR (high ASD severity)	-	SF	Mixed
Salomone & Arduino (2017)	-	Yes	-	-	-	SF	-	BR (low socioeconomic status)	-	-	SF	-	Mixed
Scahill et al. (2016)	-	Yes	-	Yes	SF	SF	-	-	-	SF (low ASD severity)	-	BR (lack of support)	Mixed
Shindor (2019)	-	Yes	Yes	-	-	-	-	SF (high socioeconomic status)	BR (busy schedule and marital problems)	BR (high ASD severity)	-	SF	Mixed

Study	Interventions' characteristics				Environmental characteristics			Participants' characteristics			Interventionists' characteristics		Significant
	Knowledge-focused support	Skill-focused support	Psychological support	Coordination support	Adaption HBIs to be culturally appropriate	Adaption HBIs to be delivered online	Educational support in a group-based format	Parents' socioeconomic status	Family's issues	Severity of children's ASD symptoms	Competency	Level of support	
Shire et al. (2016)	Yes	Yes	-	-	SF	-	-	SF (high socioeconomic status)	-	-	SF	SF	Yes
Suppo & Mayton (2014)	Yes	Yes	-	-	-	SF	-	-	-	-	SF	SF	Yes
Taylor (2014)	-	Yes	-	-	-	-	-	BR (low socioeconomic status)	BR (busy schedule and marital problems)	BR (high ASD severity)	-	-	Mixed
Tran (2018)	-	Yes	-	-	-	SF	-	-	-	-	SF	SF	Yes
Turner-Brown et al. (2019)	-	Yes	-	-	-	-	-	SF (high socioeconomic status)	-	-	SF	SF	Yes
Valeri et al. (2019)	-	Yes	-	-	-	-	-	SF (high socioeconomic status)	-	SF (low ASD severity)	SF	SF	Yes

Note. Supportive Factors (SF) and Barriers (BR).

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Chapter 3

Autism Effects on Families and a Potential Solution in the Kingdom of Saudi Arabia

As discussed in earlier chapters, research has made tremendous gains in the understanding and treatment of Autism Spectrum Disorders (ASD) since the subject was first presented in the literature in 1943 by Leo Kanner (Sterwald & Baker, 2019). However, across the world, the empirical research on ASD and available services for children with ASD and their families is uneven (World Health Organization, 2019), with many countries lacking the needed resources to adequately address the issue and allow children to thrive. The Kingdom of Saudi Arabia (KSA), an example of a low-resource country, has made a concerted effort in recent years to provide supportive, inclusive services for persons with disabilities, including children with ASD and their families (King Salman Centre for Disability Research, 2022). However, there is still a lack of empirical research, trained professionals, and available services within KSA, particularly in rural areas of the country (Alallawi et al., 2020; Alkhateeb et al., 2022; Alnemary, 2017).

Although the available information would suggest a lower rate of diagnosis of ASD in KSA as compared with developed countries, this is most likely due to under-reporting because of limited prevalence statistics (Taha & Hussein, 2014; Zeina et al., 2014). The underdiagnosis of ASD in the country is also likely because of the lack of trained professionals and the availability of appropriate diagnostic tools (Alnemary et al., 2017; Kelly et al., 2016). Encouragingly, however, there has been a focus over the past decade in KSA on the translation of ASD diagnostic screening tools into Arabic and adjustments of the protocols for cultural appropriateness (Alallawi et al., 2020; Alkhateeb et al., 2022). Overall, there is a severe lack of evidence-based ASD-related education and professional practices within KSA (Alallawi et al.,

2020; Kelly et al., 2016). More research is needed to understand better the needs of families and their children with ASD and improve the quality of services in terms of diagnostic services, early interventions, and parental training programmes in KSA (Alallawi et al., 2020; Alnemary et al., 2017).

This literature review aims to explore the breadth and depth of empirical research conducted by scholars in KSA and nearby Arab countries consistent with KSA culture to understand the knowledge and available services for persons with ASD within the country's context. Identifying what is known about the current research landscape and available support and services for families of children with ASD within the Saudi community will provide more information to assess the support needs most effectively for this particular population.

Methodology

Inclusion Criteria

The authors included studies that were: a) conducted about ASD in the Saudi community and nearby Arab countries, b) studies published in English or Arabic, c) studies regarding families of children (age 12 and under) with ASD, c) studies that investigated the impact of ASD on families. There were no inclusion or exclusion criteria regarding the studies' designs or publication dates to gain more comprehensive information regarding the experiences and needs of families.

Article Selection

The initial electronic database search identified 6,738 studies. The titles of these studies were scanned, and all titles that did not indicate a relationship to families of children with ASD in Saudi Arabia and nearby Arab countries were removed, with 288 studies remaining. All duplicate studies were removed, with 211 studies remaining. The included studies were selected in two steps to determine if the studies met the inclusion criteria for full-text review. The first

step was that the titles and abstracts of these 211 studies were read independently by both authors. The calculation of inter-observer agreement resulted in a further 148 studies being excluded. The second step was a full-text review of the remaining 63 studies, and those that did not meet the inclusion criteria were eliminated, with 27 articles remaining. All the identified research was conducted within the past decade; publication dates ranged from 2012 to 2022. The reviewed studies included 24 peer-reviewed research articles and 3 doctoral theses, and the studies' locations included: Riyadh (n=5), Jeddah (n=4), Arar (n=1), Madina (n=1), Taif (n=1), across multiple KSA cities (n=8), and research in neighbouring Arab countries which included KSA (n=7). These studies provide important information regarding the needs of families of children with ASD in KSA and nearby Arab countries.

Data Extraction

The authors developed a coding guide to extract data from the included studies that met the inclusion criteria of this literature review regarding the impacts of ASD on families in KSA and nearby Arab countries. The coding guide identified answers for open-end questions, including the availability of ASD services, families' awareness and perceptions regarding ASD, and the impacts of ASD on families' quality of life. The first author extracted data following the coding guide, and the second confirmed the data. The third author resolved the conflicts regarding the extracted data between the two authors. Three broad themes were identified, including 1) The need to improve the quantity and the quality of available ASD services, 2) The need for information and support for families regarding the causes and symptomatology of ASD, and 3) The need for psychological and social support to improve the quality of life and well-being of families of children with ASD. See Table 2 for more information about the reviewed studies.

Results

Availability of Services

A significant gap was identified between the need and availability of ASD services across cities in KSA, resulting in many children with ASD not receiving needed early interventions (Alnemary, 2017). As a result, this contributes to the higher severity of ASD symptoms (Khusaifan & El Keshky, 2022; Omer, 2014). Of the reviewed studies, more than 50% (n=16) discussed the perceptions of families of children with ASD regarding the availability and quality of ASD services, including identified variables that impact access to accurate diagnosis and research-based interventions for children with ASD in KSA. Accessing diagnostic services was indicated as a major problem in several studies (n=10). Many families had to travel to other cities in KSA or neighbouring countries, which required significant financial resources and created logistical issues for families. For example, many children are likely to experience significant delays in receiving a diagnosis, which is one factor in not receiving ASD interventions. The uneven distribution of services was also an area of concern reported by parents in many studies (n=11), with few public and private schools which serve children with ASD in KSA overall and are generally located only in major cities (Alallawi et al., 2020; Kelly et al., 2016).

Further, available services often focus more on health care than the educational, behavioural, and occupational services children with ASD may need. This scarcity of services promotes many inequities. These families are left with few options, either unable to access services or utilising services provided by practitioners with insufficient training.

Quality of Services

Lack of Well-Trained Professionals and Researchers

Reviewed studies (n=5) discussed the early stage of practitioner training and the lack of research for ASD in KSA compared to other countries. Resulting in a severe shortage of qualified practitioners to deliver research-based interventions, as few universities (n=11) in KSA offer graduate programmes in the ASD field in KSA (Keller et al., 2016). These programmes focus on theoretical rather than practical training, which is insufficient to prepare practitioners to deliver evidence-based educational interventions to children with ASD (Keller et al., 2016). Additionally, more research is needed to understand how to support families and children with ASD within the context of the Saudi culture regarding evidence-based interventions and parental support. This represents a significant problem regarding needed information and support for families with children with ASD.

The recent systematic review conducted by Alallawi et al. (2020) indicated a lack of studies that addressed ASD evidence-based interventions and parental training programmes in this region. This highlights a need for additional quality research to fully address the needs of families and their children with ASD in KSA. Specifically, information is needed to address the significant issues experienced by families, including the role of culture in diagnosis, treatments, and evidence-based practices.

Awareness of ASD among Saudi Families of Children with ASD

The reviewed studies highlighted the need to provide more support for families regarding awareness of ASD and the disorder's characteristics and causes. Studies that investigated the level of parental awareness and understanding (n=6) for Saudi families indicated misinformation regarding ASD aetiology, effective support, and treatments. For example, Alyami and colleagues

(2022) assessed the ASD knowledge of Saudi families. They found that the participants did not understand genetics as a cause of ASD and had limited ASD knowledge overall. There was also evidence (n=2) that Saudi families were likely to decide which treatment to access for their children based on cultural practices rather than scientific information. Providing families with appropriate information and training may allow them to make treatment decisions for their children with ASD that will support better outcomes (Alnemary, 2017; Alqahtani, 2012)

According to this review, Saudi families' ASD awareness and decision-making practices for their children's treatments are not well-researched. This lack of information can be a barrier between health and educational professionals and families of children with ASD in KSA to provide comprehensive services. Further research is needed to understand the implications of culture in diagnosing and treating ASD. Some studies showed that families' culture and belief systems impact their decision-making regarding their children's disorders (Alnemary, 2017; Alqahtani, 2012). Parental training programmes which support the families' awareness and understanding of ASD will allow them to make informed decisions regarding their children's treatments, but only if the training aligns with the families' culture and belief systems.

The Quality of Life among Saudi Families of Children with ASD

Furthermore, these reviewed studies (n=11) measured the quality of life among Saudi families of children with ASD, which showed an equally important need for support. The results of this review indicated that parenting children with ASD negatively impacted families functioning and well-being. For instance, several studies (n=7) have investigated the psychological health of Saudi families of children with ASD. The results showed that they suffer from mental health issues, including parental stress (Alenazi et al., 202; Alshaigi et al., 2020; Althiabi, 2021; Meny & Hayat, 2018), anxiety, and depression (Alsayed et al., 2018; Alshahrani

& Algashmari, 2021; Khusaifan & El Keshky, 2022). These mental health issues were associated with the severity of ASD symptoms and unmet needs of families because of a lack of professionals and social support. Moreover, some of the reviewed studies (n=3) have assessed the prevalence of stigmatization among Saudi mothers related to parenting children with ASD. which indicated that they experience a higher level of stigma as a result of a lack of public ASD awareness (Alshaigi et al., 2020; Sulaimani, 2018; Sulaimani & Gut, 2019). Thus, Saudi mothers of children with ASD felt isolated because of low self-efficacy in managing their children's disorders across community settings. In addition, Saudi mothers' coping strategies were overprotective parenting and Islamic healing, such as prayer (Sulaimani & Gut, 2019). See Table 2 for more information

The findings of the studies investigated the impacts of ASD on Saudi families of children with ASD, which showed lower quality of life and complex unmet needs. Parental training programmes are essential to support families of children with ASD to address their reported needs, such as helping them to deal with their children's disorder and to cope with their mental health issues. Educational and psychological interventions can improve families' awareness, self-efficacy, and well-being.

Discussion

The Potential Solutions for the Scarcity of ASD Services within KSA

There is limited research overall regarding support for children with ASD in KSA. Most of the available research focuses on the perceptions of families of children with ASD, including the availability and quality of services and the effect on the quality of life of the families (Alnemary et al., 2017; Kelly et al., 2016; Zeina et al., 2014). However, research that works to develop effective support for children with ASD and their families is lacking. Universities in

KSA need to contribute to research to support evidence-based teaching methods to children with ASD and develop and train practitioners who can effectively diagnose the disorder and implement research-based interventions a priority (Alshaigi et al., 2020; Taha & Hussein, 2014). Research that further investigates the perceptions and difficulties experienced by families of children with ASD will assist in developing culturally appropriate and socially valid interventions by families in KSA (Alotaibi & Almalki, 2016; Alqahtani, 2012; Kelly et al., 2016). A better understanding of the needs of families of children with ASD in an appropriate cultural context will assist in the development of supportive systems to provide appropriate services and research-based interventions to increase positive outcomes for children with ASD and support their families (Rodgers et al., 2021; Scahill et al., 2016). ASD services and interventions must be based on proper research. However, the content and delivery adaptations, which consider the family's culture, lifestyle, and socioeconomic situation, are essential (Alnemary et al., 2017; Alotaibi & Almalki, 2016; Kelly et al., 2016).

Professionals in the field of ASD can adapt the existing ASD evidence-based interventions to be appropriate for Saudi culture and increase the ASD resources to be available for caregivers as well as fit parents' expectations and needs (Alnemary et al., 2017; Alotaibi & Almalki, 2016; Alqahtani, 2012). For instance, parental training programmes are an instrumental part of ASD services to address the needs of families and their children with ASD in the home setting (Bearss et al., 2015; Leaf et al., 2018). HBIs can increase awareness of children with ASD, leading to informed decision-making in the future without compromising their cultural beliefs and traditions (Alnemary et al., 2017; Alotaibi & Almalki, 2016; Alqahtani, 2012) to ensure that children with ASD are receiving appropriate ASD services. Thus, there is a pressing

need to provide parental support programmes for families of children with ASD that reflect their psychological, educational, and behavioural unmet needs in KSA.

Previous research has demonstrated that with HBIs, families can implement interventions effectively to provide needed services for their children with ASD (Blake et al., 2017; Leaf et al., 2018). Some of the documented benefits of parental training include a reduction in the symptomatology of ASD, an increase in the time and contexts in which needed behaviour modification strategies can be used, and a greater likelihood that the skills taught can be generalized across settings (Bearss et al., 2015; Blake et al., 2017; Kato, 2018). In addition, the advantage of HBIs is the opportunity for families to be more involved in the intervention. There are many advantages to including parents in the development of the treatment through implementation and having this take place within the natural environment of the child's home (Leaf et al., 2018).

Overall, this may result in improved skills for the child and a strengthening of the parent-child relationship. Furthermore, HBIs within the home also reduce costs to the family and eliminate barriers, such as transportation and uneven availability of services across KSA (Alallawi et al., 2020; Alnemary et al., 2017). Thus, HBIs can provide a realistic option allowing families to support the better development of their children with ASD and eliminate financial and emotional challenges created by travel within KSA or extended travel abroad to seek services.

Table 2

The Needs of Saudi Families of Children with ASD

Study	ASD-Community Services			Awareness of ASD Among Saudi Families of Children with ASD		The Quality of Life Among Saudi Families of Children with ASD	
	Diagnostics Service	ASD interventions	Lack of well-trained professionals and researchers	ASD causes	Decision-making practices	Parental mental health issues	Stigmatisation
Abualhommos et al. (2022)	Yes	Yes	-	Yes	-	-	-
Abusukkar (2020)	-	-	-	Yes	-	-	-
Abusukkar (2014)	Yes	Yes	-	-	-	-	-
Alenazi et al. (2020)	-	-	-	-		Yes	-
Alyami et al. (2022)	-	-	-	Yes	-	-	-
Alnemary (2017)	Yes	-	-	Yes	Yes	-	-
Alnemary et al. (2017)	Yes	Yes	-	-	-	-	-
Alnemary et al. (2017)	Yes	-	Yes	-	-	-	-
Al-Otaibi & Al-Maliki (2016)	Yes	Yes	-	-	-	-	-
Alqahtani (2012)	-		-	-	Yes	-	-
Alrajhi (2021)	Yes			-			
Alsayed et al. (2018)	-	-	-	-	-	Yes	-
Alshaigi et al. (2020)	-	-	-	-	-	-	Yes
Alshahrani & Algashmari (2021)	-	-	-	-	-	Yes	-
Al-Shibli & Hamdoun (2019)	Yes	Yes	-	-	-	-	-
Alzahrani & Brigham. (2017)	-	-	-	Yes	-	-	-

Study	ASD-Community Services			Awareness of ASD Among Saudi Families of Children with ASD		The Quality of Life Among Saudi Families of Children with ASD	
	Diagnostics Service	ASD interventions	Lack of well-trained professionals and researchers	ASD causes	Decision-making practices	Parental mental health issues	Stigmatisation
Babatin et al. (2016)	Yes	Yes	-	-	-	-	-
Barah et al. (2020)	Yes	Yes	-	-	-	Yes	-
Kelly et al. (2016)	-	Yes	Yes	Yes	-	-	-
Khusaifan & El Keshky (2022)	-	-	-	-	-	Yes	-
Meny & Hayat (2018)	-	-	-	-	-	Yes	-
Omar (2014)		Yes	-	-	-	-	-
Sulaimani (2018)	-	-	-	-	-	-	Yes
Sulaimani & Gut (2019)	-			-			Yes
Taha & Hussein (2014)	-	Yes	Yes	-	-	-	-
Zeina et al. (2014)	-	Yes	Yes	-	-	-	-
Yunis (2015)	-	-	-	-	-	-	-

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Chapter 4

Online Group-Based Educational Training for Parents of Children with Autism Spectrum Disorders in the Kingdom of Saudi Arabia

Preface

The literature reviews in Chapters 1 and 3 indicated that more information was needed on effective ways to support families in KSA with children with ASD. This chapter's reports on the research project were to fill the gap in this critical area in ASD research in the Saudi community. This study assessed the families' ASD awareness and decision-making regarding their understanding and their practices of ASD treatment to manage their children's disorders. This study was the first stage of HBI to increase families' ASD awareness before participating in the second stage of HBI.

The manuscript was submitted for consideration to a peer-reviewed research journal and is currently under review.

Abstract

There is limited research regarding Autism Spectrum Disorders (ASD) within the Kingdom of Saudi Arabia. This suggests a limited understanding of ASD which may promote acceptance of practices that are non-research-based. This study aims to understand if providing culturally appropriate parent education will enhance Saudi female caregivers' ability to support their children with ASD by increasing their understanding and awareness of ASD. The online group-based, interactive training sought to provide information regarding ASD, including the causes, symptomatology, misconceptions, and how to locate and access available services. An overview of the foundational principles of Applied Behaviour Analysis (ABA) is provided. The female caregiver participants (n=15) were administered a pre and post-test to measure changes in perceptions and knowledge of ASD after engaging in the online training. Pre-test data indicate a moderate level of knowledge of ASD; however, decisions were often based on inaccurate information, and sourcing effective support was difficult. Post-test results indicate encouraging changes to participant perceptions and knowledge. The programme procedures are presented and discussed, including suggestions for culturally appropriate content and identification of possible barriers to administration. Limitations of the study and future research directions are discussed.

Keywords: autism spectrum disorders, children with autism, educational training, online parent training, Kingdom of Saudi Arabia

Online Group-Based Educational Training for parents of children with Autism Spectrum Disorders in the Kingdom of Saudi Arabia

Parents are responsible for supporting their children and seeing that their physical, emotional, and educational needs are met to help promote positive present and future outcomes (Sim et al., 2017). However, for parents of children with special needs, these responsibilities can be difficult and create more stress for parents; this is especially true for families which include children with Autism Spectrum Disorders (ASD) (Dieleman et al., 2018). Children with ASD often have significant impairments in communication and social skills, and restrictive and repetitive patterns of behaviour or interests persist across the lifespan (American Psychiatric Association, 2013). These impairments present challenges across all areas of the child's life, including their school, family, and community (Klaiman et al., 2015). The efforts of families of children with ASD to support their children can be stressful and may negatively impact all aspects of their lives, including marital relationships, employment, and mental health (Likhitweerawong et al., 2020; Pearson & Meadan, 2018). For instance, research has linked high levels of parental stress because of inadequate ASD services with a lack of confidence in their ability to manage challenging child behaviours (Sim et al., 2017). Families worldwide have similar perceptions, experiences, and challenges, making the needs of their children with ASD unmet (Alotaibi & Almalki, 2016; Jafarabadi et al., 2021; Marsack-Topolewski et al., 2020).

The worldwide scarcity of research-based, culturally appropriate resources and services to support children with ASD and their families has been noted as a human rights concern by the World Health Organisation (2014). The lack of available services in countries with few resources is much more acute. When families must search for information and services independently, they are more likely to be drawn to inaccurate information and stereotypical myths (Barrio et al.,

2019). However, the majority of ASD research and subsequent provision of services to address critical issues, such as ASD prevalence, symptoms, and evidence-based interventions, have taken place in Westernised countries with greater available resources (Lee & Meadan., 2021; Rice & Lee, 2017). Providing research-based, culturally appropriate resources for children with ASD and their families must be made available across all countries and regions to support children with ASD and families who care for them.

Autism Research in Saudi Arabia

ASD research is scarce within the Arab nation of Saudi Arabia, which often leads to an inadequate understanding of families with children with ASD who live in this area regarding the prevalence, causes, and management of ASD (Alnemary, 2017; Alrajhi, 2021; Kelly et al., 2016). However, harbouring misinformation, often fostered through cultural or religious understandings or practices, is likely to lead to the acceptance and use of ineffective, non-research-based treatments and interventions for their children (Alnemary, 2017). Common treatments often sought include reciting the Quran, visiting a traditional or religious healer, or diet therapy, including items like honey, camel milk, vitamins, and diet supplements (Klein & Kemper, 2016). Besides the potential detriment to their children's well-being, these practices may prevent the acceptance of appropriate and effective research-based interventions. Expanded, high-quality community resources are urgently needed to provide effective ASD services, including parental support, to improve the quality of life for families (Alrajhi, 2021). Research demonstrates that if families hold accurate perceptions and a clear understanding of the causes and effective treatments of ASD, they are more likely to seek out research-based interventions and accept support for their children (Kuravackel et al., 2018; Lee & Meadan, 2021). Therefore,

appropriate and accurate parental education regarding ASD causes and symptomatology is vital for parents to effectively support their children's well-being (Oliver, 2018).

Parent training was proposed by Lovass (1987) more than three decades ago as an effective way to support families and their children with ASD. Since that time, the effectiveness of parental training to support children with ASD has been broadly investigated (O'Donovan et al., 2019; Parsons et al., 2017). Significant evidence of parental ability to implement different types of ASD interventions with high fidelity results in positive behavioural child outcomes in children (Akhani et al., 2021; Mueller & Moskowitz, 2020). Parental training is important because it goes beyond the educational setting to provide continuous support for children in a natural environment (Kuravackel et al., 2018). Further, the support of families through effective training, which allows them to both understand the disorder and effectively support their children, has been shown to result in positive outcomes for families, such as an increase in self-efficacy and a reduction of stress (Iadarola et al., 2018; Leaf et al., 2018).

Culturally Appropriate Parental Training

Research conducted within the past decade suggests that although there is a focus on how to assess the needs of families of children with ASD (Alallawi et al., 2020; Alnemary et al., 2017; Kelly et al., 2016), there is little awareness of the disorder, few evidence-based interventions, and inadequate numbers of practitioners. This makes it difficult for families to receive appropriate training and support (Alnemary et al., 2017; Kelly et al., 2016). Further, most parental training programmes for parents of children with ASD have been developed in Western countries, generalising diverse cultures difficult (Barrio et al., 2019). Supporting families through the delivery of training and interventions which are culturally appropriate increases the

chances that erroneous perceptions around ASD are corrected and decreases the dependence on non-evidence-based interventions.

In this study, adaptations were made in the educational training as to the content, method of delivery, and scheduling to consider the culture and lifestyle of the family. For instance, all instructional materials were presented in Arabic, and all pictures presented in materials were culturally sensitive, including presenting persons in traditional clothes with familiar food and other items that are culturally and/or religiously acceptable. The trainer and the parent participants were all female because it is more of the cultural norm in those remote areas. In other parts of the country, in metropolitan areas such as Jeddah or Riyadh, videotaping and both parents present is more readily accepted.

Effects of Covid-19 and Online Parental Training

Globally, families and their children with ASD face challenges in using quality ASD services because of the disparity of available ASD resources across countries. However, their need for more support increased due to reduced available services during the Covid-19 pandemic (Baweja et al., 2021). Regardless, families of children with ASD remain responsible for the care of their children and must continue to try to access ASD services even during the pandemic, resulting in a scarcity of economic and emotional resources, increased stress, and social isolation (Althiabi, 2021; Baweja et al., 2021). Providing parental training through web-based technologies effectively addresses the unmet needs reported by families of children with ASD (McGarry et al., 2019; Tran, 2018). This information can be valuable when developing support to overcome barriers often experienced by families, such as lack of transportation or childcare or providing services for families who live in remote areas (Ferguson et al., 2022; Little et al., 2018). Delivery of online training and support is also generally cost-effective, allowing greater

access to services to support families and their children (Salomone & Arduino, 2017). In addition, providing parental support and training in a culturally appropriate manner within the family home or through electronic communication is effective during the pandemic and should be considered in the future (Baweja et al., 2021). To overcome of unavailability of ASD services and ensure children with ASD continue receiving support during future emergency circumstances.

Purpose of Study

This study sought to evaluate the effectiveness of culturally appropriate parental training delivered electronically to Saudi female caregivers to improve an accurate understanding of ASD symptomatology and causes and understand how to source appropriate support for their child and family. It is crucial to understand if well-delivered research on home-based training, considering the specific characteristics of the family and community, can provide a viable method for professionals to assist parents (Wakeford, 2017). Parents of children with ASD who have an accurate understanding of the disorder, can access appropriate services, and have a clear understanding of effective strategies to address their children's needs, may experience an improved quality of life for both themselves and their children (Iadarola et al., 2018; Kuravackel et al., 2018).

Method

Research Design

This study utilised a mixed methods design to gather comprehensive information regarding parental training. Mixed methods are an approach that attempts to answer research questions by collecting and analysing both quantitative and qualitative data (Johnson et al., 2007). Because this study seeks to measure the efficacy of the parent training and the cultural

appropriateness according to the parents' perceptions, it is essential to draw upon multiple types of information (Odem, 2005). Before the training began, the participants completed a demographic questionnaire to ensure that the participants met the study criteria (Ferguson et al., 2022; Leach, 2012; Shindorf, 2019). The survey was modified from previous studies to cover the information presented in the educational training (Alnemary, 2017; Stone, 1987). The survey questions were administered pre and post-intervention to assess changes in participant perceptions in three areas: causes and symptomatology of ASD, community ASD resources and services, and ASD treatments. The survey included 16 questions in three formats: a) multiple choice, b) true and false, and c) yes and no with further explanation. See Table 3 for more information.

Table 3

The Pre and Post-Test Survey

	Questions
Multiple Choice	1-Which of the following is the cause of autism? 2- How can autism be diagnosed? 3- What treatment do you think your child would benefit most from? 4-What do you think is the best resource for information about autism?
True and False	5- Individuals with autism do not make eye contact. 6- Autism is a developmental disorder. 7- Autism affects boys more than girls. 8- The prevalence of autism is higher among families who have lower socioeconomic status. 9-Autism is a communicable disease. 10- Autism symptoms are very different among individuals with autism. 11- All individuals with autism are talented. 12- There is one treatment to “cure” all individuals with autism. 13-All individuals with autism are nonverbal.
Yes and No with Explanation	14- Do you think you are responsible for your child's condition? If yes, please explain 15- Do you know the rights of a child with disabilities and their family according to Kingdom of Saudi Arabia special education laws? 16- Are you confident in your ability to help your child?

Recruitment and Ethical Considerations

The participants were recruited through a public organisation that provides services for children with ASD and their families in an under-resourced area of Saudi Arabia. This study was part of a broader study that had previously sought and received ethical approval (HRE2020-0386). Because one of the study objectives was to better understand the cultural appropriateness of the training within the context of Saudi Arabia, only families who were Saudi Arabian citizens or long-term residents were contacted and invited to participate. All families who responded were provided with study information, including a description of the training, time involved, responsibilities, and possible benefits, to make an informed decision about their participation.

Participants

The participants met the study's eligibility criteria, including 1) Saudi females, 2) long-term female residents with children with ASD, and 3) who had not previously received parental training regarding ASD. This inclusion criterion was developed specifically for this study to control study variables and measure the effectiveness and cultural appropriateness of the training.

Participant Characteristics

The participants (n=15) who enrolled in the study responded to the demographic questionnaire administered by the researcher via telephone. Results of this questionnaire indicated that the participants (all female primary caregivers of children with ASD) ranged in age from 25 to 44 years old, with education levels varying from completion of elementary school (n=3), high school (n=4), and postgraduate degrees (n=7, bachelor’s degree), (n=1, post graduate diploma). Finally, the self-reported economic status of the participants varied from low to moderate income levels.

Measures and Procedure

Pre- and Post-Test

Before beginning the training, the participants were asked to complete an online survey to measure their knowledge and understanding of ASD. The survey, presented in Arabic, the native language of the participants, consisted of 16 questions and took about 30 minutes to complete. The same survey was again administered after the conclusion of the training to understand the differences in the knowledge and perceptions of the participants.

Barriers and Support

Consideration of environmental and cultural factors to support effective participant engagement was important (Blake et al., 2017). The training was presented in an online, group-based format, via the Zoom® platform, with the timing of the training sessions negotiated among the group to be manageable for the participants. The online training format overcame potential transportation and childcare barriers for the participants. Further, face-to-face training would unlikely be successful as the training took place during the Covid-19 pandemic.

The participants' varying confidence levels and competence regarding information technology were also a barrier. For example, some participants did not have the knowledge and ability to use devices or programmes to perform technological skills. Therefore, additional individual training tutorials to support the correct download and use of Zoom® were conducted with the participants (n=6) by the researcher as needed via mobile phone and WhatsApp® calls or messages. Although individual customs and practices vary with different families and locations throughout KSA, in general, gender segregation is practiced in many remote areas. Therefore, it is significant to mention that in this study, part of a larger study, the participants, and the trainer (researcher), were all female. Particularly since the next training phase included

individualised training within the home, some participants may not have been willing to work with a male trainer, especially within their home.

Content of Educational Training

The researchers developed educational training materials based on the needs of families of children with ASD in KSA. Previous research indicated that families of children with ASD in KSA experience three areas of need, including a lack of understanding of ASD, managing their children's disorders, and difficulty accessing available ASD services (Alotaibi & Almalki, 2016; Alrajhi, 2021). For instance, the educational sessions provided information and facts surrounding ASD which would be relevant to parents, such as causes, symptoms (American Psychiatric Association, 2013), and specific evidence-based interventions, including the principles of Applied Behavioural Analysis (ABA) to support the management of challenging behaviours (Leach, 2012). In addition, the parents were provided information regarding myths and common misinformation surrounding ASD and how to locate local resources to support the child and family. See Table 4 for more information as to the content of sessions.

Table 4

Training Session Content

Session	Content	Corresponding pre and post questions
Session 1	Introductions, training overview. Autism causes, symptoms, and prevalence	1, 5, 6, 7-11, 14
Session 2	Importance of early intervention using evidence-based behavioural interventions	2, 3, 12
Session 3	Laws, regulations, and rights of individuals with disabilities in Saudi Arabia. Availability and accessibility of ASD services.	4, 15
Session 4	Overview of Applied Behaviour Analysis (ABA) principles.	2, 3

Session	Content	Corresponding pre and post questions
Session 5	Strategies to support appropriate behaviour, including daily/visual schedules	3, 12
Session 6	Reinforcement: identification and use of appropriate reinforcers	3, 12
Session 7	Planned ignoring: appropriate use for non-aggressive behaviours.	3, 12
Session 8	Compliance: compliance strategies to increase cooperative behaviours.	3, 12
Session 9	Task analysis to increase self-care skills.	3, 12
Session 10	Data collection methods: using data to guide instruction.	3, 12

Structure of Training Sessions

The training was completed over two weeks, with 10 sessions held for approximately one hour each for a total of 10 hours of training. All of the participants (n=15) completed the 10 hours of training; however, across individual sessions, there were occasional absences because of family schedules, doctor appointments, or other unexpected circumstances which arose. In these cases, the trainer arranged individual make-up sessions to deliver all content to all participants. The purpose of the first session was for the trainer and the participants to introduce themselves and learn more about the training, including the overall content to be presented and how they could expect the training to benefit their children and themselves. The remaining sessions were interactive, consisting of a presentation of the topic content by the trainer, supported by PowerPoint® slides with opportunities for participant questions and discussion around related experiences. Each session ended with interactive discussions providing opportunities to correct any misconceptions and served as an informal session evaluation. These discussions also supported the development of collaborative peer-to-peer support by sharing experiences and known local resources.

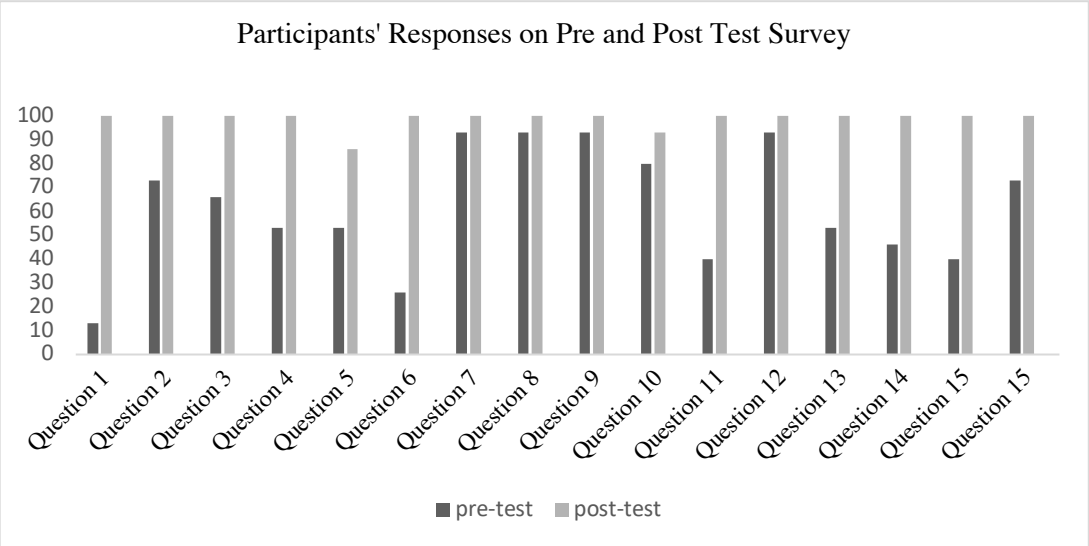
During sessions which included training to support sourcing and utilising specific resources, the trainer modelled how to find links, complete required forms, and submit requests for information or services via the screen sharing function. The trainer utilised video clips demonstrating the strategies and encouraging participants' questions and discussion for each session, including behaviour management strategies.

Results

This study aimed to understand if culturally appropriate parent training, delivered with fidelity through electronic means, can effectively support parents of children with ASD. The training targeted three broad educational areas: 1) the causes and symptoms of ASD; 2) identification and sourcing of supportive community and educational resources; and 3) specific strategies to support behaviour management and development of self-care skills appropriate for use in the home environment. The pre and post-test measured areas one and two, with the measurement of the third area conducted after the second phase of parent training, which took place in the context of the larger study. See Figure 3

Figure 3

Participant Pre and Post-Test Survey



Causal Factors of ASD

Parents of children with ASD need to have an accurate understanding of their child's condition if they are able to provide effective support. Further, if parents do not understand the scientific causes of ASD, they may blame themselves or their actions and be more likely to seek out ineffective or even dangerous practices (Alnemary, 2017). Overall, the parents' answers in the pre-test indicated a general lack of understanding of the causes of ASD. Questions 1, 6, 9, and 14 specifically sought to gauge the parents' understanding of the causality of ASD. Questions 7 and 8 inquire about the related issue of prevalence; specifically, do the parents believe that autism is related to gender (question 7) or influenced by a family's socioeconomic status (question 8)?

The parents' answers, particularly in questions 1 and 6, would indicate that the parents felt the causes of ASD are both out of their control or even a punishment for something they had done wrong, such as an act of God or allowing their children to excessively engage in screen time. The majority of the parents (73%) did not recognise ASD as a developmental disorder. However, in question 9, all but one (n=14) of the parents correctly answered that ASD is not a communicable disease. Particularly troubling is the information gathered in question 14. The parent's responses were split almost evenly (n=7 yes, n=8 no) to the query: "Do you think you are responsible for your child's condition?" The parents were further prompted to provide their reasoning for their beliefs.

The parents who answered yes provided answers which indicated a sense of guilt for their direct actions, such as: *"I did not take folic acid during pregnancy"* (Participant 4) and *"I gave my child a vaccination"* (Participant 9). Several responses suggested feelings of inadequacy in their parenting skills: *"I could not raise him"* (Participant 6). Even more specifically, "*I have*

allowed my child to watch TV for a long time and neglected my child" (Participant 14) or *"I have allowed my child to watch TV"* (Participant 15). As to prevalence, the majority of participants (n=14) answered yes to question 7, which asked if ASD is more prevalent in boys rather than girls. However, most participants (n=14) correctly understood that children from families of low socio-economic status are no more likely to have ASD than their counterparts with more social or economic capital.

The parent post-test responses are encouraging and indicate that the training effectively promoted significant changes in the understanding of the causes and prevalence of ASD. The parents responded 100% that ASD is a developmental disorder. It is caused by genetic and environmental factors, is not based upon gender or a family's socio-economic status, and relinquished their guilt-inducing beliefs that their child may have ASD because of something they did or did not do.

Autism Symptomology

When parents have a good understanding of the symptomatology of ASD, it is easier for them to understand how to support their children, including making appropriate parenting and behavioural management decisions (Lee & Meadan, 2021). This may be because the parents have more accurate perceptions regarding the progress or abilities of their child and a clearer understanding of the diversity of needs and abilities of persons with ASD (James, 2019). Further, they can be better informed as to what specific ASD services their children may be eligible to receive and what types of programmes would target specific symptoms of ASD. There is evidence that parents who more fully understand the symptomology of ASD and how to support their children are likely to experience a higher degree of self-efficacy and improvements in mental health and overall well-being (Iadarola et al., 2018; Lichtlé et al., 2020).

The pre-post assessment included four questions that sought to assess the participants' perceptions and understanding of ASD symptomatology and the overall diverse nature of ASD. The questions targeted common misconceptions around people with ASD, including lack of ability to make eye contact (question 5), high levels of talent for all individuals with ASD (question 11), all individuals with ASD are non-verbal (question 13), and finally that individuals with ASD have diverse characteristics overall (question 10).

The pre-test responses indicated that overall, the majority of the parents understood the diverse nature of ASD, with 80% of the participants (n=12) answering correctly that "symptoms are very different among individuals with autism" (question 10). However, across the individual symptoms, the parents' understanding was less accurate; in all three questions, the parents were split, with approximately half answering correctly. Specifically, 46% of the parents held the misconception that all individuals with ASD do not make eye contact. 60% of the parents answered "true" to the incorrect statement: all individuals with ASD are talented. 46% of the participants believed that all individuals with ASD are non-verbal. The post-test answers prove that the training supported change for many parents' misconceptions and misinformation. All parents answered question 10 regarding the overall diverse nature of ASD correctly, and correct answers for the three questions querying stereotypical perceptions of ASD range from 86% to 100% correct.

Parental Ability to Identify and Source Community and Educational Resources

According to research conducted by Alotaibi and Almalki (2016) regarding parents of children with ASD in Saudi Arabia, parents often struggle to understand how to source appropriate resources and services to support their children. This is a problem as parents may be more likely to make uninformed decisions regarding appropriate services and be vulnerable to

the influence of practitioners with insufficient expertise in this area. Providing appropriate training and information as to evidence-based practices and increasing parents' awareness may reduce the use of interventions and treatments that are not evidence-based (Klein & Kemper, 2016). Further, parents who understand what services are available and know their children's rights will be better positioned to advocate for their children. Therefore, five questions were designed to better understand parents' perceptions about appropriate sources of information (question 4), including diagnosis procedures (question 2), effective methods of treatment (questions 3 & 12), and awareness and understanding of their child's rights (question 15).

Parents must understand how their children can be correctly diagnosed and what types of treatment will be most effective if they can support their children. Question 2 queried the appropriate method of diagnosis; in the pre-test, 73% of participants correctly responded that clinical observation is the best method of diagnosis. However, 26% of the participants responded, "I don't know". Question 4 was related to this concept, as parents were asked what they felt was the best source of information about ASD. Only about half of the participants (53%) believed that professionals were the best source of information, with the other half of the participants divided between the internet (26%) and other parents (20%) as the best source of information.

Question 12, also related to the heterogeneous nature of ASD, asks the parents to answer true or false as to whether one treatment will treat all individuals with ASD. Only one parent incorrectly answered this question, with the majority (93%) responding with "false". The responses to question 3 were more concerning: the parents were asked what treatment they felt would most benefit children with ASD, 66% of the parents chose behavioural therapies, and 13% chose speech-language therapies. However, two parents named camel milk the best choice, and

one parent listed the Quran as the best therapy for their child with ASD. More than half of the parents (60%) responded “no” to question 15: “Do you know family and child rights under the special education laws in the Kingdom of Saudi Arabia.” The post-test results for this section of questions indicated that the parents had gained significantly in their understanding as to how to source valid information and support for their children, as the answers to all (questions 2, 3, 4, 12, 15) were 100% correct. Finally, the parents were asked about their confidence in supporting their children with ASD. In the pre-test, 73% of the parents returned a positive response, but in the post-test, all parents said yes and were confident they could support their children effectively.

Discussion

Providing high-quality services to support children with ASD is important to help them develop and learn to their full potential. Parents of children with ASD need appropriate information and training to support and advocate for their children (Alallawi et al., 2020). There are challenges for all families of children with ASD; however, the needs are particularly acute in areas with less access to research-based services and trained professionals, such as Saudi Arabia (Babtain et al., 2016). Further, families have a right to access research-based support consistent with their cultures and beliefs (Blake et al., 2017). The purpose of this study was to better understand if parental training, delivered with fidelity and designed to be culturally appropriate, can improve parental understanding of ASD, including how to recognise and source accurate information. It is also important to manage barriers, such as lack of transportation and childcare, and the study provided important information on the feasibility of electronic delivery.

Research Findings

This study aimed to investigate the perceptions underlying the practices used by Saudi families with ASD children and to provide them with educational training. While establishing

and delivering the online educational training, the Saudi families' culture and needs were considered. Therefore, virtual training for families of children with ASD was both effective and accessible. It was a major support component with covid crisis, which would not have access to ASD services. The findings of this study indicated that participant perceptions of ASD were increased in the post-test compared to the pre-test after attending the educational training sessions. The outcomes of this study are encouraging, with strong indications that effective programmes can be delivered to families online. However, future programme developers should not discount the importance of personalised, ongoing support of the trainer for families across all aspects, including technology usage to continual encouragement to engage.

Further, the peer social support provided through group training can be useful in many ways, including developing social groups for ongoing peer-to-peer support and helping support families' mental health overall (Ault et al., 2021). Some factors contributed to the successful completion of the study and influenced the participants' overall outcomes. The study was conducted during the Covid-19 pandemic, which presented many difficulties for families, including unavailability of ASD services, changes in health service availability, home lock-down conditions, limited social interaction, and a cessation of global travel (Baweja et al., 2021). Although these challenges presented additional stress and difficulties for families, there was also motivation to engage and commit to the study activities because there were few other options.

Similar to previous research findings (Ferguson et al., 2022; Little et al., 2018; Tran, 2018), online access to services and training proved to be a viable option for families of children with ASD living in rural areas as well as overcoming barriers resulting from illness, such as Covid-19. Therefore, online, evidence-based training and interventions can be recommended for families in similar circumstances. However, it is important to note the significant impact of the

trainer's support on learning. Online training that is more self-directed is unlikely to be as effective. This study included a high level of support from the trainer, including individual pre-training tutorials for the participants who struggled with technology. Another important factor was the flexibility in the timings of the training sessions, which were determined after discussion and consensus of the participants as to convenient times. The trainer also conducted individual make-up sessions for the participants that were occasionally absent due to illness or other obligations. This overall flexibility and willingness to communicate consistently between sessions via mobile phone or WhatsApp® messages likely assisted with developing a trusting professional relationship between the trainer and participants. They supported the early identification of any challenges or misunderstandings.

Limitations and Implications for Future Research

This study consisted of a small number of participants (n=15) in a remote area of Saudi Arabia. Therefore, the study's findings may not generalise to larger or different populations. More research is needed to understand how to support families with children with ASD who live in remote areas and within their cultural context (Antezana et al., 2017). No specific criteria were identified to be met by the participants to measure the attainment of the participants' knowledge and skills. A formative, qualitative assessment was completed through a question-and-answer session of approximately 30 minutes at the end of each session to address questions and concerns and uncover any misunderstandings. However, future researchers should consider providing the participants with the opportunity to complete a brief, individual assessment of the content of each session. This would provide more objective data on the participants' understanding of the content. The participants in this study had a broad level of education attainment. Those with low levels of education struggled significantly with the use of technology and required additional

support. This variable should be considered when planning future online-based training for parents.

The children of the participants were aged between 4 to 8 years and had been diagnosed with ASD at different ages. Therefore, there were varying levels of knowledge and understanding of ASD across the participants. Future research should consider the length of time since diagnosis as a criterion for inclusion in studies.

Conclusion

Supporting families and their children with ASD is imperative to their full potential, as is their right according to the United Nations: Convention on the Rights of the Child (1989). Following the initial diagnosis of ASD is critical for families and their children; therefore, training soon after the diagnosis or learning that their children might be at risk for ASD would be most beneficial (Landa, 2018). Timing is crucial as early intervention is most important for the best behavioural and educational outcomes. Developing supportive, evidence-based programmes with appropriate psychological, educational, and behavioural components is critical, reflective of Saudi families' needs and respecting their culture (Alnemary et al., 2017; Alotaibi & Almalki, 2016; Kelly et al., 2016).

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Chapter 5

A Home-Based Intervention for Children with Autism Spectrum Disorder: Outcomes for Saudi Arabian Families

Preface

This chapter includes the third publication of this thesis to evaluate the effectiveness of a culturally appropriate HBI for Saudi families and their children with ASD. This study was the second stage of HBI to increase families' self-effacing to implement ASD evidence-based strategies to support their children's development in social communication and self-care skills and decrease their challenging behaviours in KSA.

Link: http://www.iier.org.au/iier32/alanazi.pdf

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Abstract

Parents of children with Autism Spectrum Disorder (ASD) often struggle to find appropriate educational and behavioural resources to support their children. These resources are particularly lacking in countries with fewer resources overall. This study aimed to evaluate the effectiveness of a culturally appropriate training programme for parents, specifically mothers, of children diagnosed with ASD in Saudi Arabia. The participants included Saudi parents (n=5) and their children (n=5), all 4 to 8 years of age. The single-subject study utilised multiple probes across participants' design. The researcher and each parent collaboratively developed a Home-Based Intervention (HBI) to teach a specifically targeted skill to their child. Observational data were collected to measure the accuracy and reliability of the parents' ability to deliver instruction to their children. The primary dependent variable was the parents' fidelity in treatment implementation, and the secondary dependent variable was the children's acquisition of targeted skills. Results indicate a high level of fidelity of intervention (parents) with a high acquisition rate (children) of the targeted skills. Implications of the study, including limitations and future research, are discussed.

Keywords: autism spectrum disorder, children with autism, Saudi Arabia, home-based intervention, parent training.

A Home-Based Intervention for Children with Autism Spectrum Disorder: Outcomes for Saudi Arabian Families

Families of children with disabilities often face economic, social, and cultural difficulties in meeting their children's special needs (Asa et al., 2020). These difficulties must be addressed effectively due to the negative impact likely on parents' physical and mental health. Due in part to the behavioural challenges that children with autism spectrum disorders (ASD) present, families of children with ASD often face unique challenges resulting in even higher levels of parental stress and a decreased quality of life (Dieleman et al., 2018). These stressors may strain family relationships, resulting in parenting disagreements on how to manage child behaviour and even contribute to divorce (Dieleman et al., 2018). In addition, families who lack extended family or community support find themselves socially isolated (Galpin et al., 2018).

Families report feeling overwhelmed when first receiving a diagnosis of ASD for their child. They may feel an increased sense of responsibility while trying to manage new and unfamiliar information regarding their child's choices and decisions regarding the best care and education (Dieleman et al., 2018).

The supports and resources available to families (Fearon & Sonuga-Barke, 2021; Kelly et al., 2016), as well as their understanding of and previous experience, including interactions with persons with ASD, vary broadly according to the family's ethnic and socioeconomic background and geographic location (Hebert, 2014; Jafarabadi et al., 2021; Su et al., 2021). For instance, families who live in economically deprived communities (Longtin & Principe, 2016), rural or remote areas (Hoogsteen, 2011), or those who face racial discrimination (Wagner et al., 2021) often experience disparities in ASD information and services, such as lack of educational

services, a lower likelihood to obtain an early diagnosis, and lower quality ASD services (Bishop-Fitzpatrick & Kind, 2017).

Raising children with ASD in such limited-resource areas can be more stressful for families for a number of reasons, including the unavailability of supportive programming for their children, the scarcity of trained professionals, and a lack of community support (Alnemary et al., 2017; Wagner et al., 2021). Even when both parents are present, available research suggests that cultural dynamics in some worldwide locations make it more likely that mothers of children with ASD will be the parent most involved with their children's day-to-day care and education. This may also contribute to increased stress levels for the mothers (Alshaigi et al., 2020; Althiabi, 2021; Devries, 2016).

Saudi Arabia is an example of an area with low ASD resources and a broad cultural practice of the mother acting as the primary child caretaker (Alotaibi & Almalki, 2016; Althiabi, 2021; Babatin et al., 2016; Zeina et al., 2014). Previous research regarding ASD in Saudi Arabia highlights significant cultural and familial challenges, with little information on the availability and effectiveness of evidence-based practices for individuals with ASD within the country (Alqahtani, 2012; Kelly et al., 2016; Taha & Hussein, 2014).

Available research focusing on the quality and quantity of ASD services in Saudi Arabia highlights significant unmet needs according to the perspective of Saudi families (Alotaibi & Almalki, 2016; Alnemary et al., 2017). These needs include a lack of community awareness, little accurate information about ASD, more support needed for evidence-based practices, particularly to support early intervention for children with ASD, and greater community resources for individuals with ASD with a goal of improved quality of life for the entire family (Alotaibi & Almalki, 2016; Alnemary et al., 2017; Taha & Hussein, 2014; Kelly et al., 2016).

Particularly in rural areas, Saudi mothers of children with ASD often report feeling stigmatised. They find it very difficult to locate and access services for their children (Alshaigi et al., 2020; Sulaimani, 2018), which may result in higher levels of psychological stress, including a higher level of anxiety and depression (Alotaibi & Almalki, 2016; Meny & Hayat, 2018).

One solution for families and their children in Saudi Arabia and similar areas of the world which may lack sufficient resources to support children with ASD may be the training of parents to implement home-based intervention (HBI) using culturally appropriate materials (Alkhalifah & Aldhalaan, 2018; Alotaibi & Almalki, 2016; Althiabi, 2021). HBI is a specific method of intervention used to support individualised parental training for delivering a specific ASD intervention in a naturalised setting. It is well-accepted within the ASD field (Bearss et al., 2015). Research emphasises the advantages of HBI for individuals with ASD and their families (Popovic, 2017; Scahill et al., 2016; Shindorf, 2019), including providing the family with appropriate knowledge and skills to address their children's needs in specific areas. Parents can be trained to appropriately address challenging behaviours, teach replacement behaviours, and increase social communication, self-management, and academic skills (Popovic, 2017; Scahill et al., 2016; Shindorf, 2019).

Furthermore, research indicates that psycho-educational information provided to parents as a part of HBI training has benefits that can improve the quality of life for parents of children with ASD (Iadarola et al., 2018; Kuravackel et al., 2018; Little et al., 2018). HBI has effectively improved parents' mental health, self-efficacy, well-being, and overall quality of life (Iadarola et al., 2018; Kuravackel et al., 2018; Little et al., 2018). In addition, HBI is cost-effective, eliminating the transportation burden and providing a viable option to support families in remote areas (Carr & Lord, 2016; Pickard et al., 2016).

This study aimed to evaluate the effectiveness of a culturally appropriate HBI programme for parents, specifically mothers, of children diagnosed with ASD living in Saudi Arabia. An important component of this study was direct instruction provided by the researcher and the close interactive communication between researcher and participant to honour and support the cultural dynamic of the communities of the families in Saudi Arabia. Data was collected to measure the effectiveness of the parent training to effectively teach targeted skills of their children diagnosed with ASD.

Method

Children with ASD and their families are a very heterogeneous population, with a wide range and severity of symptoms, making it difficult to generalise or identify sufficient cohorts of similar subjects for a large-scale study or to make statistically meaningful comparisons (Odom et al., 2005). Single-subject design is a scientific method that allows for consideration of small or even individual numbers of subjects, using systematic observation and measurement of the individual's behaviour to provide an understanding of the effectiveness of the intervention. Single-subject design methods allow the individual to act as their own control. Baseline (before treatment) behaviour is measured along with the measurement of behaviour during specified points in the treatment.

Design and Procedures

In this case, the single-subject study utilised multiple probes across participants' design. (Johnston & Pennypacker, 1993). It included two areas of evaluation, specifically, the ability of the parent participants to implement the HBI after the development of the intervention, which has been specially designed in collaboration with the parent to teach specific targeted behaviours

to their child. Second, the intervention's effectiveness is measured by the child's ability to achieve target behaviours.

Ethical Considerations and Recruitment

Before beginning the study, families of children who were students at a publicly funded school for children with ASD in a Saudi Arabian city were contacted via the school administration and invited to participate in a larger study. Before beginning the larger study, details of the study were submitted for ethical approval (HRE-2020-0386). The families contacted were limited to Saudi Arabian citizens or long-term residents. The study's objective was to gauge the cultural appropriateness and effectiveness of the specifically modified instruments of assessment and intervention. The initial phase of the larger study included theoretical training for families regarding the causes and symptomatology of ASD. After the training, the parent participants were provided information and invited to participate in this study. Five parent participants agreed and provided informed consent to participate in this study, which would develop a customised HBI for their children.

Participants

The participants for this study were mothers of children diagnosed with ASD; specific selection criteria included: (1) female caregivers of children with ASD who were Saudi citizens or long-term residents; (2) their children were between 4 to 8 years of age and previously diagnosed with ASD; and (3) the female caregivers had not previously received applied behaviour analysis (ABA) applied training of HBI. Although the participants had completed educational training in ABA theoretical concepts as a part of the previously mentioned larger study, they had not received applied ABA training.

Participant Characteristics

A total of 10 participants (5 parent and child pairs) enrolled in the HBI. In instances where information in this study is specific to either parents or children, this will be expressed as parent or child participants. All participants were native to Saudi Arabia, and Arabic was the primary language spoken in their homes. As per the recruitment criteria, the parent participants were all female and their children's primary caregivers. Their ages ranged from 31 to 44 years, and their level of education varied, with one participant who completed elementary school, another who completed high school, and three that held bachelor's degrees. All parent participants were stay-at-home mothers, except one was a school teacher. However, during Covid-19, she was working from home. According to the reported income, the families ranged from very low to mid-socioeconomic standing in their community. The child participants, all male, ranged in age from 5 to 8 years. According to the data from the CARS-2 assessment (see Step 2 below), one child exhibited mild symptoms of ASD, 3 fell within the moderate range, and one scored in the severe range. Each parent participant collaborated to determine their child's target behaviour and an appropriate corresponding HBI.

Determination of Target Behaviours and Intervention

The target behaviour and most appropriate intervention for each child were determined through a consultative and collaborative three-step process between the researcher and parent participant. The three steps consisted of: (1) gathering information from the parents; (2) formal assessment of the level of ASD symptomatology; and (3) target behaviour determined by consensus between the researcher and parent after considering the information obtained in step 1 and 2, including the development of an appropriate intervention.

Step 1: Demographic and behavioural information. Information was gathered from the parent through telephone discussions between the researcher and parent to understand the family demographics, child behaviours, and culture and lifestyle priorities of the family. A questionnaire was developed after a thorough review of relevant studies to guide the discussions, which discussed the type of family and child information highly relevant to the development of effective HBI for children with ASD (Alnemary, 2017; Kato, 2018; Leach, 2012, pp. 26-29; Nicksic-Springer, 2016; Shindorf, 2019).

Family demographic questions included information regarding the age of all family members, parents' marital status, education, occupation, and level of family income. Questions were also asked regarding the child participant as to any health conditions, diagnoses, and medication. Open-ended qualitative questions were utilised to gather critical information, including the parents' goals and priorities for their children, challenging behaviours, family routines, lifestyle preferences, and the child's interests and preferences. The questionnaire is presented in Table 5.

Step 2: Formal Evaluation of Level of ASD Symptomatology. The researcher administered, by telephone, the Arabic adaptation (Alqahtani, 2017) of the *Childhood Autism Rating Scale*, 2nd ed. (CARS-2) (Schopler et al., 2010) to the parent participants, to determine the severity of ASD symptomatology of each child participating in the study. The CARS-2 is a rating scale widely used to determine the severity of ASD symptoms in individuals. The Arabic adaptation of this instrument, supplied by the cooperating school, was most appropriate, as all participants were native Arabic speakers. A licensed psychologist from the school trained the researcher in using the CARS-2 assessment tool and oversaw administration to the parent participants.

Step 3: Determination of Target Behaviour and Appropriate Intervention. The researcher and each parent participant discussed by telephone the information gathered in steps 1 and 2 and agreed on a specific target child's behaviour. The researcher developed an appropriate HBI to address the target behaviour, taking into account the strengths and needs of both the family and the child. Each parent participant reviewed the HBI for their child to ensure the intervention was acceptable to the target behaviour and consistent with their lifestyle and particular home environment.

Table 5

Parent Questionnaire (Conducted in Arabic)

Item		Item statement
Women caregivers' demographic background	1	How old are you?
	2	What is your relationship with the child?
	3	What is your marital status?
	4	What is your highest level of education?
	5	What is your occupation?
	6	What is your annual income?
	7	Do you receive any government funding for the diagnostic and educational services your child receives?
Child's demographic background	8	How old is your child?
	9	What is your child's gender?
	10	What is your child's primary diagnosis?
	11	At what age was your child diagnosed with ASD?
	12	Does your child have other disabilities? If yes, please describe.
	13	Does your child have any diagnosed medical conditions? If yes, please describe.
	14	Does your child take prescribed medication?
	15	Does your child have any co-occurring conditions such as hyperactivity, sleep disturbance…etc.? If yes, please specify.
	16	Has your child received preschool services?
	17	Does your child attend a public or private school? How many hours per week?
	18	Please list any educational or behavioural services that your child currently receives.
	19	What are your child's favourite activities, toys, and/or food?

Item		Item statement
Caregivers' priorities	20	What are some of your child's strengths and weaknesses?
	21	What is the most concerning behaviour that you would like to change?
	22	Why did you choose this specific behaviour?
	23	What do you believe is the cause of this behaviour? What purpose do you think this behaviour serves for the child?
	24	Can you explain how you currently respond to this behaviour? How do other family members respond to the behaviour?
	25	Have you previously sought help to change this behaviour? If yes, describe.
	26	Did you learn skills to help manage the behaviour?
	27	Does this behaviour occur in different settings?
	28	What do you think would be an appropriate replacement behaviour?
	29	Describe your family's daily routine, including mealtime, playtime, and outdoor social activities.
	30	What do you feel are potential barriers/challenges that may impact your ability to implement new strategies at your home?
	31	Are there any other family members that also help with child care?
	32	How many hours do you work outside your home each week?
	33	What would be the best location to conduct the training and implement strategies in your home?

The HBI developed for each participant through the collaborative process was based on ABA principles and previously developed evidenced-based parent training programmes and HBI to meet each child's and their family's needs (Connolly, 2015; Cooper et al., 2007; Scahill et al., 2016). An important consideration of the HBI development was the usability and appropriateness according to the culture and lifestyle of each family. Lifestyle considerations included aspects of each family, such as family schedules and available space in the home. Cultural factors included providing all instructional materials in the family's native language, Arabic, and assuring that pictures in the materials were consistent with religious and cultural norms, including portraying persons in native dress and references to familiar food and items. The intervention occurred

within each participant's home in an area that was comfortable, familiar to the child, and appropriate for the targeted behaviour and skills, such as a family room or an outside play area.

Measures and Variables

This study involved the measurement of two dependent variables: (1) the ability of the parent to deliver instruction based on ABA methodology to their children with fidelity; and (2) the children's level of skill acquisition as determined by each child's demonstration of appropriate targeted behaviours previously determined through the three-step consultative process.

The researcher collected pre-intervention observational data in the family homes to establish a baseline of proficiency for both dependent variables. In each case, the parent participant with the most stable baseline began the intervention first. The same sequence was followed with each participant until all participants had received the intervention. After the completion of the intervention, the researcher conducted post-intervention probes to ensure that the participants maintained the skills they learned without the intervention remaining in place.

Dependent Variable 1: Level of Parental Skill in Instruction Delivery

The researcher conducted the training and observational data collection through individually scheduled home visits for each parent participant for all project phases, i.e., pre-intervention probes, intervention, and post-intervention probes. Baseline data were collected on the parent participants' implementation of ABA strategies using the specifically designed fidelity checklist shown in Table 6 (Nicksic-Springer, 2016; Phosaly, 2017; Taylor, 2014). As previously mentioned, the parent participants had received theoretical training on ABA principles as a part of a larger study. However, no applied ABA training had been received by any of the study participants or through other sources. Through that training, the participants (parents) learned

about some of the basic principles of ABA, such as reinforcement, punishment, and schedules of reinforcement. Therefore, the pre-intervention data documents the ability of each parent participant to deliver the instruction to their child, including relevant data collection, without systematic training from a qualified professional.

Table 6

Fidelity Checklist for Participant Implementation

	Criterion	Yes	No
1	Have materials available and organised (datasheet, child's preferred reinforcement, items, etc.).		
2	The caregiver gained the child's attention before making a request.		
3	The caregiver delivered an appropriate stimulus as written in the programme plan (word and sound).		
4	The caregiver allowed time (3-5 seconds) for the child to respond.		
5	The caregiver immediately reinforced the correct response or ignored inappropriate behaviour.		
6	The caregiver presented the antecedent stimulus multiple times in a single session. Note: A specific criterion was not set due to the different skills being targeted for each child		
7	The caregiver implemented the strategies as stated in the programme plan.		
8	The caregiver provided a prompt (verbal, gestural, or physical) to achieve the target behaviour.		
9	The caregiver used the monitoring progress data sheet to record the child's response.		
10	The session ended with the child demonstrating mastery of the skill.		

Note. Checklist adapted from Phosaly (2017).

During the pre-intervention probes, the researcher observed the participants (parents) working with their children on the target behaviours, including their ability to document child responses on specifically designed data collection sheets, and documented both the parent and

child responses. During the pre-intervention phase, the number of observations differed for each participant due to the study design: multiple probes across participants. Because of this, the participants who began the intervention later in the study received more observations. The same measures were conducted in pre- and post-intervention probes for the participants (parents and children). A criterion of at least 80% accuracy was set for the post-intervention probes to determine the participants' level of skill acquisition.

Dependent Variable 2: Child's Acquisition of Skills

Skill acquisition was determined by each child's ability to respond correctly to the previously selected target behaviour. The parent participants collected frequency or rate data for their child regarding the target behaviour. The participants presented 10 trials in pre-intervention and post-intervention probes for frequency measures. As for rate measures, the participants collected data on the number of times the target behaviour occurred in 10 minutes in pre-intervention and post-intervention probes. Table 7 describes the target behaviour for each child, the method of measurement, and the type of intervention materials used.

Table 7

Description of Participant Goals, Interventions, and Materials

Mother/child code	Parents' goals for child	Intervention	Materials	Data collection method
A	Increase social communication	Picture exchange communication system (PECS)	Programme plan, data collection sheet, pictures for child's favourite food and daily activities as reinforcers	Frequency data collection sheet
B	Increase self-care	Task analysis	Programme plan, data collection sheet, visual steps of toileting, social reinforcement (praise), tangible reinforcers	Frequency data collection sheet
C	Elopement	Antecedent intervention	Programme plan, data collection sheet, green and red cards, social reinforcement (hug and praise), tangible reinforcers	Frequency data collection sheet
D	Increase social communication	Instruction in question-asking procedure	Programme plan, data collection sheet, child's favourite food, drink, and toys/activities, opaque bags	Frequency data collection sheet
E	Increase social communication	Instruction in question-asking procedure	Programme plan, data collection sheet, child's favourite items and activities, opaque bags	Frequency data collection sheet

Intervention

The intervention sessions took place in the participants' homes. They were approximately one hour in duration at a frequency of three times per week during a convenient time for the participants. A task analysis was completed for each targeted behaviour, determining the steps followed during each phase, including the pre-intervention, intervention, and post-intervention phases. The researcher modelled the correct delivery of the antecedents, data collection of correct and incorrect responses, and appropriate presentation of consequences for correct and

incorrect responses. After the researcher presented the models, the participants (parents) had the opportunity to deliver the trials themselves, receiving immediate feedback from the researcher.

The participants were encouraged to deliver the intervention to their children daily beyond the three weekly training periods. The researcher was at the participants' homes three times a week to work with the participants (parents) and collect inter-observer agreement. Therefore, all parents practiced delivering the intervention, including collecting and recording data a minimum of three times per week with the set criterion of 80% accuracy.

Inter-observer Agreement

A high percentage of agreement among two or more independent observers is essential to demonstrate the reliability of the data collected to measure the same event/behaviour (Watkins & Pacheco, 2000). To determine the level of inter-observer agreement, the number of steps completed accurately by the participant was divided by the total number of steps, then multiplied by 100 according to the checklist shown in Table 2. The researcher collected inter-observer agreement data during the three weekly intervention training sessions until the participants delivered instruction with 80% accuracy.

Results

A total of 10 participants (parents n=5, children n=5) completed the study. Participant responses between pre-intervention probes, intervention, and post-intervention sessions were compared. The results showed significant improvements in the participants' (parents) ability to deliver instruction to their children with fidelity. Across all participants (parents and children), pre-intervention baseline data shows that the parents delivered instruction with 0 percent accuracy and correct responses for the children was 0. This is expected since the parents had not received any training in intervention delivery at this point. However, during the intervention

training, the data indicated that the parents were able to deliver the interventions with 70% to 100% accuracy. Post-intervention probes indicate that this accuracy was maintained, with a range of 80 to 90% accuracy. The following sections will report specific data for each parent and child participant pair. See the graphed data in Figures 1 (parent participants) and 2 (child participants).

Participant A Results

Participant A (parent) delivered instruction to her child in 9 sessions with an average of 87% accuracy during the intervention. In the post-intervention probe, Participant A (parent) delivered instructions to her child with 100% accuracy. Participant A (child) received instruction in 9 sessions with an average of 79% accuracy. Participant A (child) demonstrated 100% accuracy in post-intervention probes when performing the target behaviour.

Participant B Results

During the intervention, Participant B (parent) delivered instruction to her child in 11 sessions with an average of 86% accuracy. In the post-intervention probe, Participant B (parent) delivered instructions to her child with 90% accuracy. Participant B (child) received instruction in 11 sessions with an average of 77% accuracy. Participant B (child) demonstrated 80% accuracy in post-intervention probes when performing the target behaviour.

Participant C Results

During the intervention, Participant C (parent) delivered instruction to her child in 11 sessions with an average of 87% accuracy. In the post-intervention probe, Participant C (parent) delivered instructions to her child with 66% accuracy. Participant C (child) received instruction in 11 sessions with an average of 79% accuracy. Participant C (child) demonstrated 100% accuracy in post-intervention probes when performing the target behaviour.

Participant D results

During the intervention, Participant D (parent) delivered instruction to her child in 10 sessions with an average of 86% accuracy. In the post-intervention probe, Participant D (parent) delivered instructions to her child with 80% accuracy. Participant D (child) received instruction in 10 sessions with an average rate of .49 correct responses per minute. Participant D (child) maintained a level of .6 correct responses per minute when performing the target behaviour in post-intervention probes.

Participant E results

During the intervention, Participant E (parent) delivered instruction to her child in 10 sessions with an average of 90% accuracy. In the post-intervention probe, Participant E (parent) delivered instructions to her child with 100% accuracy. Participant E (child) received instruction in 10 sessions with an average rate of 1 correct response per minute. Participant E (child) maintained 1.4 correct responses per minute when performing the target behaviour in post-intervention probes.

Results for the five participants are shown graphically on the next two pages (860 and 861), in Figure 1: Parent intervention results, and Figure 2**:** Child participants' results, including pre-intervention probes, the intervention sessions, and the post-intervention sessions (use the "zoom in" function in web reader or PDF reader to obtain legibility).

Research Findings and Discussion

The purpose of this study was to better understand if a specifically designed and culturally appropriate HBI programme could effectively support mothers of children with ASD who live in areas with few resources, such as Saudi Arabia. In addition, we wanted to learn more about effective ways to train parents to teach their children with ASD in home-based settings

using ABA evidence-based practices to understand more about effective ways of supporting parents while they teach their children using the ABA evidence-based practices. Further, we wanted to learn more about the effectiveness of adopting the HBI to meet participants' cultural and lifestyle needs (parents and children).

Addressing a Critical Need

There is a lack of quality services and support for children with ASD and their families in Saudi Arabia, particularly in rural and remote areas (Alnemary et al., 2017; Alotaibi & Almalki, 2016). Currently, there is a lack of accurate information as to the prevalence of ASD and specific numbers of families and their children in need of services overall in Saudi Arabia, and the government is actively taking steps to acquire this information. The Custodian of the Two Holy Mosques approved a national survey in October 2021.

Figure 4

Parents Graphed Data of HBI

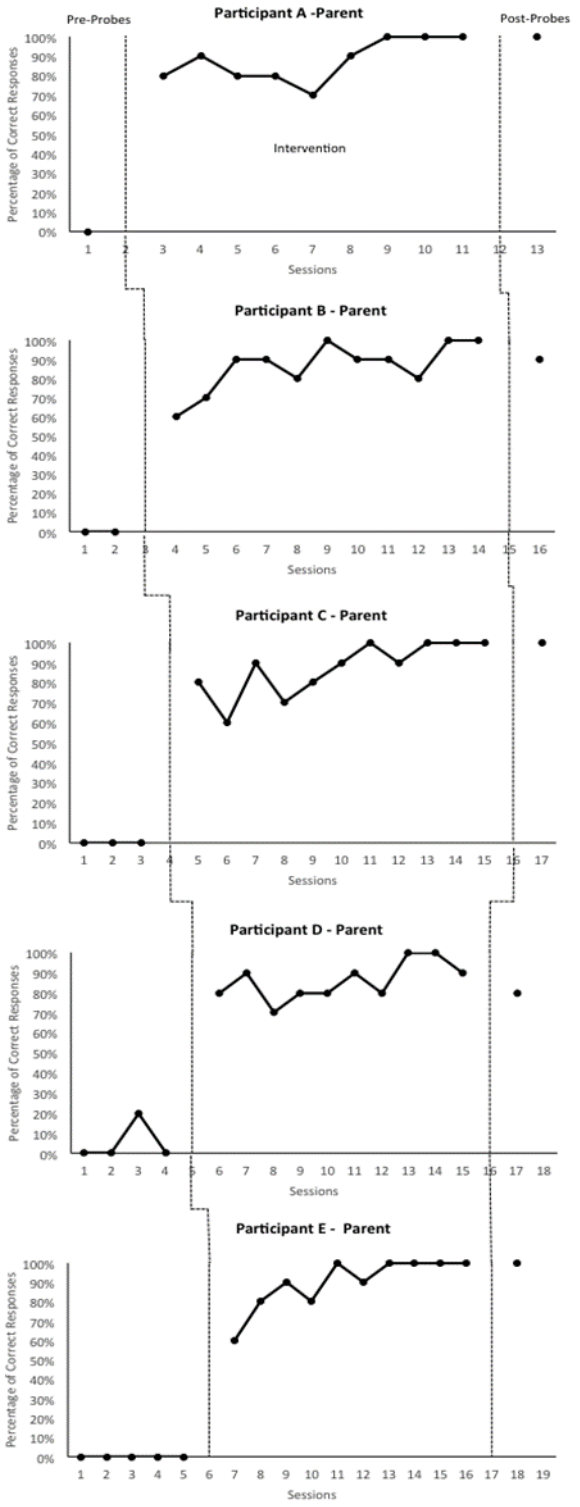
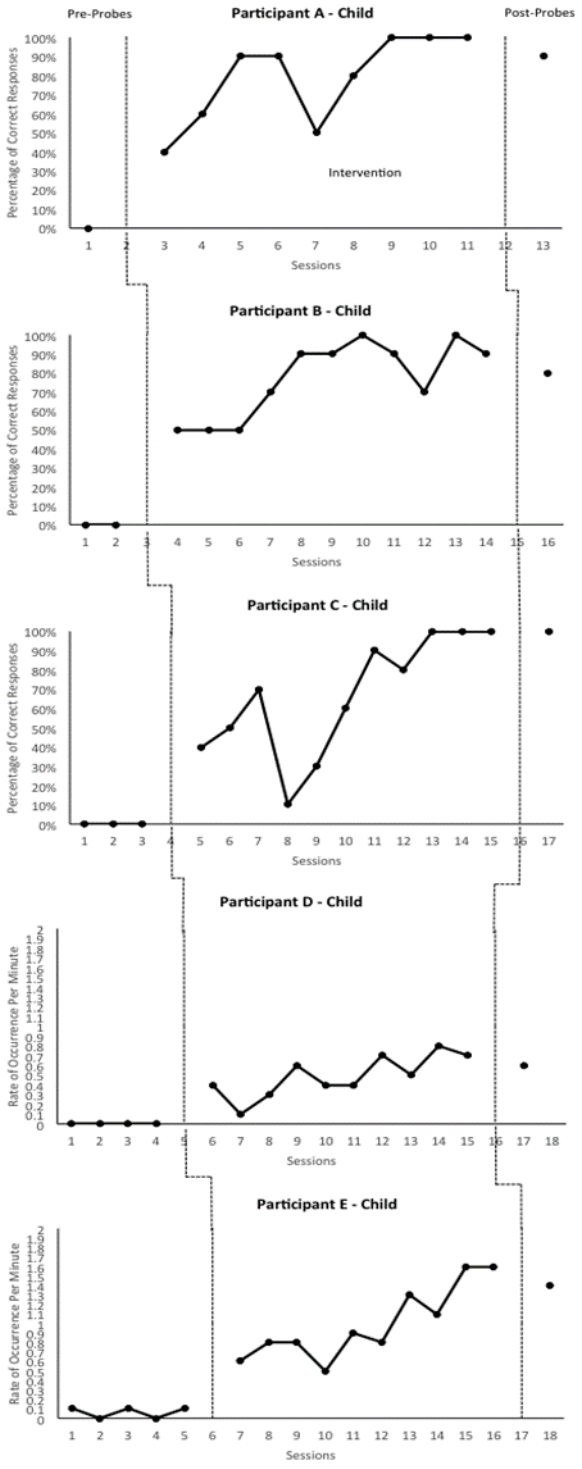


Figure 5

Parents Graphed Data of HBI



Consistent with the results of this study are those of a recent scoping review conducted by Lee and Meadan (2020). They investigated the viability of training parents of children with ASD in low-resource areas, as defined by the United Nations, to implement interventions for their children with ASD in their naturalistic home setting. Although available research is scarce, consistent with this study, the results indicated that HBI might be a viable solution to support families who reside in low-resource areas such as Saudi Arabia. A crucial finding, it should be noted, was the strong relationship between adapting the intervention to be culturally appropriate and the parent's willingness and ability to successfully implement the intervention (Lee & Meadan, 2020).

Cultural Fit and Individualisation for Each Family

This study's results supported previous research findings that HBI can effectively support the development of children with ASD and their families in limited-resources areas (Suppo & Mayton, 2014; Tran, 2018). For instance, Sneed (2021) compared parent-led and practitioner-led interventions and found that both groups had similar positive improvements for children with ASD.

Particular care was given in this study to ensure a good fit with the lifestyle, routines, and culture of the family and the community culture. Continual consultation with the family allowed for appropriate individualisation of the treatment plan, including specific design according to the family's culture and lifestyle. This component allowed the researchers to include further details, such as training timings, identification of feasible strategies for parents to implement, and choosing target child behaviours that are priorities for the family. All of these are critical elements that influenced the level of motivation and commitment of the parent participants. This purposeful effort to understand the parents' priorities for their child and family and involve them

in developing an effective intervention provided agency for the families. It was important to develop an effective intervention that met their needs.

Importance of Individualised In-Home Supportive Instruction

Although the parent participants had received theoretical training on ABA principles before beginning the study, the baseline data demonstrated that this important foundational knowledge was insufficient for successful parent implementation of the strategies. The participants could not systematically teach their children without access to written materials from their previous training. The in-home instruction with immediate feedback and modelling from the researcher significantly influenced how the participants (parents) delivered instruction to their children.

The parent's level of commitment and motivation appeared to influence outcomes. The researcher encouraged all parents to implement the strategies in their daily routines. However, the parent-reported level of implementation outside of the times the researcher was present varied. This reported level of implementation was consistent with parent and child outcomes. In general, the participants (parent/child pairs) that engaged more with the interventions demonstrated more positive outcomes. Specifically, the parents were better able to deliver the intervention, and the children demonstrated improvements regarding the targeted behaviours.

Effects of Covid-19 and Other Environmental Factors

Environmental factors, such as the presence of a worldwide pandemic, Covid-19, and the remote location of the families, meant that very few other resources were available. Receiving services and education at centres and schools was not an option for an extended period during the pandemic; therefore, HBI, with appropriate precautions such as social distancing and mask-wearing, was a much-needed solution for families. Despite these necessary restrictions, parents

may have been more motivated to engage and follow through with the training since they had fewer outside distractions and more time at home.

The current study demonstrated that HBI might be an important method to support families of children with ASD during Covid-19 because their ability to access and receive ASD services was restricted even more. Finally, the preventive health measures required by the World Health Organization during the pandemic negatively impacted children with ASD and their families (Althiabi, 2021; Baweja et al., 2022). Shortage of ASD services worldwide due to the suspension of diagnostic services, closure of centres and schools, and lack of available support from therapists and professionals are severe and negatively affect the developmental outcomes of children with ASD (Althiabi, 2021; Baweja et al., 2022). In addition, imposed social isolation presents severe psychological challenges for the families.

Limitations

This study provided important information regarding developing effective HBI for children with ASD, which are culturally appropriate for families in remote areas. However, ASD is heterogeneous, with symptoms and severity varying greatly across individuals. The needs, priorities, and requirements also differ from family to family, making it difficult to generalise across the population. In addition, the participants for this study consisted of a small number of parent and child participants; the findings may or may not generalise to other families with children with ASD.

The study, as previously discussed, was conducted during Covid-19, a worldwide pandemic, requiring necessary restrictions to protect the health of the families and the researcher. These restrictions, such as mask wearing and maintaining social distance, while necessary, also impacted the ability of the researcher to model the HBI strategies and may have impacted the

fidelity of training and data collection. Further, due to the restrictions present during the study, only one post-intervention probe was completed. Collecting additional post-intervention probes to determine whether the parents retained the skills they were taught in delivering instruction to their child would provide valuable information about the study's validity.

Video communication and recording is an effective strategy often utilised for teaching and data collection and can be particularly useful for families in remote areas. However, societal and cultural norms precluded the use of video. This limitation restricted the researcher's ability to collect inter-observer agreement data and may have impacted the results. This limitation could be mitigated if additional researchers were available to collect additional data. Finally, although the parent participants had a set performance criterion, the child participants' performance was measured only as to whether there was an increase. More specific criteria measuring the amount of increase would strengthen the research.

Future Research

This study provided valuable information as to the feasibility and effectiveness of culturally and environmentally appropriate intervention for families of children with ASD, especially those who reside in resource-poor areas such as Saudi Arabia and have little access to educational resources for ASD (Alnemary et al., 2017; Alotaibi & Almalki, 2016; Kelly et al., 2016; Taha & Hussein, 2014). This research is particularly notable as it provides information with important links between two disparate types of educational activities, specifically education and support for parents and their children with ASD.

Without appropriate knowledge, it is difficult for parents to understand how to search for resources, effectively advocate for their children, or to be able to provide at-home instruction for their children. Further, most of the research currently available regarding effective education and

support for families of children with ASD, including the effectiveness of HBI, has been conducted in Western, English-speaking countries. It is important to note that Saudi Arabia has specific rules around gender separation, particularly within home settings. Therefore, it is imperative to consider this social norm when designing interventions to be conducted with mothers within the home and only include female interventionists. More research is needed to understand how culturally appropriate, research-based HBI can support families and their children in remote, resource-poor locations (Kelly et al., 2016; Zeina et al., 2014).

It is well established that early intervention is critical for children with ASD with clear benefits which improve immediate quality of life, such as reduction of ASD symptomology, and improved long-term outcomes, such as improved functioning in academic and social settings. Therefore, future research focusing on early support for parents and their families with a recent diagnosis of ASD in Saudi Arabia is crucial. Particularly in low-resource areas such as Saudi Arabia, providing this critical support in culturally appropriate, assessable methods such as HBI, delivered with fidelity, may improve outcomes for children with ASD and support their families. This may overcome barriers such as scarcity of resources and lack of transportation, especially for families living in remote areas. Further, parental training for HBI may mitigate other negative factors, such as parental stress and financial strain, while meeting their child's needs.

HBI services can provide effective, comprehensive support for parents of children with ASD to understand the disorder, have the skills to support their child's development, and be proactive advocates to access available community and educational services (Shahidullah et al., 2018). HBI training programmes may also support reducing stress and overall parent mental health with training in coping strategies such as relaxation techniques and mindfulness-based intervention, providing more information for effective avenues of support in mental health, self-

efficacy, well-being, and parenting skills. Future research into how to provide a holistic HBI model is needed. It may help to close the gap experienced by many parents of children with ASD to access effective services that are appropriate for their values, culture, and lifestyle, no matter where they may live.

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Chapter 6

Conclusion

Research regarding the understanding, diagnosis, and support of persons with ASD has significantly advanced since Kanter's early work (Rice & Lee, 2017). However, there is still much to learn, and particularly in areas of the world with few resources, there is a need to provide education and support for families of children with ASD (DeVries, 2016; Dieleman et al., 2018; Jafarabadi et al., 2021; Marsack-Topolewski & Weisz, 2020). It is also imperative that families and their children with ASD are supported in ways that honour their culture, values, and lifestyle to be most effective.

Home-Based Interventions (HBIs) effectively provide support for children with ASD and their families (Bearss et al., 2015; Leaf et al., 2018). Therefore, this study sought to investigate the viability of using the HBI to provide support for families in KSA, a country with a limited number of trained professionals and supports for children with ASD, particularly in rural and remote areas (Alnemary, 2017; Alotaibi & Almalki, 2016; Kelly et al., 2016). An essential aspect of the study was modifying materials and information to be culturally appropriate for families in KSA. This project consisted of three phases using quantitative and qualitative data to answer interrelated research questions concerning how to structure the HBI to provide culturally appropriate, effective, and evidence-based support for families of children with ASD in KSA.

The first phase of this project was to review available research literature related to relevant elements of HBIs for families and their children with ASD. This systematic review of 43 studies provided important information on how families of children with ASD can implement research-based interventions, such as HBIs, after being trained effectively by a professional to benefit children with ASD and their families. Through the literature review, we understood the

specific variables that act as supports or barriers to delivery, including various training formats, designs, and duration of the training and intervention. The research indicates that it is crucial to accommodate specific needs that target various objectives of families and their children with ASD and include ongoing systematic training and support while considering specific families' characteristics. HBIs can also effectively increase access to interventions and support for families and their children with ASD who live in remote or limited resource areas.

Because the focus of this study was to investigate the HBI to specifically support children with ASD and their families who live in KSA, it was essential to review the available research literature specifically conducted in this area, including information about Saudi families, policies, and resources. This literature review (n= 24 studies) on the needs of Saudi families of children with ASD showed a severe lack of parental knowledge of ASD with few skills to manage their children's disorder (Abusukkar, 2020; Alnemary, 2017; Alqahtani, 2012). This review provided important information regarding the specific type of needed informational and skill support for the families of children with ASD, including the negative impact on the families' well-being likely to result from a lack of support. The information gathered from both reviews was used to develop the training and support the HBI programme and subsequent evaluation.

The Research

This research project sought to develop and evaluate a culturally appropriate HBI to support families and their children with ASD in KSA. According to the previous research, there were critical areas of need of Saudi families of children with ASD, which were addressed through two stages. In the first stage, Saudi families needed educational training to improve their knowledge of the causes and symptomology of ASD, evidence-based interventions for children with ASD, and available local ASD resources and services. Publication 2 of this project aims to

research the perceptions behind the practices applied by the Saudi families of children with ASD and deliver educational training. This online educational training considered the Saudi families' needs and culture during establishing and delivering it. Participants' results of the online educational training showed that their awareness of ASD increased. The outcomes of this study are encouraging, with strong indications that effective programmes can be delivered to families online. Therefore, virtual training for families of children with ASD was both effective and accessible. It was a major support component during the Covid-19 crisis who would not have access to ASD services. However, future programme developers should not discount the importance of personalised, ongoing support of the trainer for families across all aspects, including technology usage to continual encouragement to engage.

In the second stage, Saudi families of children with ASD needed the skills to support their children's appropriate behavioural, communication, and self-care development. HBI improved the participants' ability to implement strategies to support their children's development at home. The data of this study indicated that the HBI effectively supported families and their children with ASD. The outcomes of HBI in both online and in-person formats increased the participants' ASD awareness about their children's disorder. The evidence of this project is consistent with available research on HBIs in supporting families and their children with ASD across domains (Blake et al., 2017; Scahill et al., 2016). Therefore, the findings of this project are important for families who reside in remote or rural areas.

A critical component of effective and ethical research is that it must consider the needs and agency of the participants. This is certainly true when working with families, especially with interventions within the family home. This project considered the family's needs and included

their voices in all phases of the research. Three broad areas of consideration were access to the services, collaboration and communication, and individualisation.

Access

Providing orientation training was necessary to help the participants understand the training course's procedures and expectations, including ensuring they had the appropriate technical skills to enrol and participate in the online sessions. The online training was crucial for the families for several reasons, including overcoming challenges of transportation and children care as well as safety during the Covid-19 global pandemic. Participants needed the technical skills to enrol and confidently engage in the sessions. The HBI materials were sent electronically to the participants to be accessible whenever needed. Therefore, the participants had to understand how to access and download the materials to benefit them. The trainer also communicated with the parents and answered questions through WhatsApp® messaging. This was a platform that the participants were familiar with and comfortable using, as it is a popular platform in Saudi culture. The advantages of this type of communication are discussed further in the following section.

Scheduling flexibility was an important component of HBI stages. All families have many demands on their time; however, families of children with a disability, such as ASD, must often contend with increased illness, medical appointments, or other issues. These families' circumstances make it necessary to overcome by conducting one-to-one online training sessions or rescheduling home visits. Flexibility in delivering sessions was necessary for the families to engage consistently in the HBI (Scahill et al., 2016).

Collaboration and Communication

Collaboration between mothers and the trainer was essential to individualise the treatment plan for each child and prioritise goals in a way that could be implemented effectively within each family unit. Goals meant for each child and family increased the likelihood that the family would engage in the training and complete the tasks with a higher level of fidelity. The mothers collaborated in the HBI implementation, including selecting behaviour goals, implementing ASD strategies, and documenting child progress data. The large amount of time mothers spend with their children and families' routines was important to implementing the HBI, for instance, the HBI strategies that fit into each family's routine and the rearrangement of home environments to practice HBI strategies. This increased the opportunities to expose children to the HBI strategies, producing positive outcomes. Besides helping the families to develop appropriate skills to support their child's development, respecting their needs and values supports trust development with families. It may improve their self-confidence and sense of autonomy.

Providing families with effective methods of supporting their children also helps to ensure a continuity of care regardless of changing family circumstances or public health crises such as the Covid-19 pandemic. Supportive communication provided by the trainer through WhatsApp® messaging, as mentioned earlier, provided additional support, allowing the families to ask questions or clarify methods between the online or in-person training and overcome obstacles to implementation. Further, group WhatsApp® conversations allowed for an essential method of peer-to-peer support, including developing an organic supportive family group that may continue past the training period.

Individualisation

For maximum effectiveness, the interventions and support must be research-based, but it is also important to remember that a family home is not a clinical setting. Therefore, if the intervention is compatible, the family will likely be consistent in implementation. This study paid particular attention to respecting and supporting the family's Islamic religious and cultural practices, as this is an important aspect of life in KSA. This included consideration of parental beliefs, language, and traditions when developing training content and flexibility around scheduling. Specific consideration was also given to characteristics of the family, such as their level of education and income status. For example, the written language of the content must be easily understood, and recommended materials must be easily accessible to the families. Both the appropriateness of materials and the level of support provided by the trainer appeared to positively impact the families' motivation to persist and their ability to implement the strategies with fidelity. Although the strategies must be implemented with fidelity, details such as timing to fit the families' routine can and should be modified. Attention to these types of details increases the chances that the families will persist in the longer-term implementation of the strategies. Therefore, both the families and their children will have more significant benefits.

Limitations

This project included a small number of participants in a specific region of KSA. The results may or may not generalise to other families and their children with ASD in other parts of the world. Each family of a child with ASD is unique, with individual needs and strengths. More information is needed to understand the different aspects of support needed for families and their children with ASD, particularly in low-resourced areas of the world. Education for families to understand their children's symptomology and developmental needs is critical. The evaluation of

the training for families in this study indicated that they increased their knowledge through online training. However, the assessments were verbal, and qualitative discussions were completed as a group. This represents a limitation, as the peer discussions may have influenced the families' answers. Quantitative, objective quizzes completed individually may provide more objective information on the knowledge gained and important information on effective training.

The data for this research was gathered during the Covid-19 worldwide pandemic. There were challenges with implications regarding the scheduling of in-home sessions and the need to wear masks and observe physical distancing, which may have impacted the fidelity of the HBI.

Finally, one of the goals of the HBI provided to the families was to improve their self-efficacy to support their children's needs. However, improving families' psychological well-being was not considered a target outcome of the HBI and was not explicitly measured. Future research can investigate the relationship between improved education and family support, such as coping strategies to deal with challenges, thoughts, and feelings in raising children with ASD.

Implications for Future Research

The findings of this research are consistent with previous studies, which indicate that families share similar experiences, needs, and challenges of raising children with ASD regardless of their culture or geographical location (Su et al., 2021; Zuckerman et al., 2016). In addition, the HBI can be an effective method to support families and their children with ASD. Specific characteristics of the families must be considered to reach positive outcomes, including their lifestyle, values, and culture, must be carefully considered. This individualization aspect represents a critical area of focus for the research community around ASD. Additional studies aimed at providing support to families and their children with ASD with a focus on the culture and unique characteristics of the family would be important to help the field move forward.

Specifically, it is essential to conduct additional research across cultures to investigate the effectiveness of culturally appropriate parental training programmes to improve the ASD knowledge and self-efficacy of parents and enable them to support their children's development. This is vital to increase access to evidence-based interventions across cultures for families and their children with ASD in limited-resources areas. This training and information may assist families of children with ASD in decreasing their reliance on non-evidence-based interventions and instead direct their time, money, and effort to support their children's development by implementing effective ASD evidence-based interventions.

Professionals work with families of children with ASD, as well as for future researchers in the field of ASD. This government endeavour aims to gain accurate statistics concerning ASD diagnoses in Saudi Arabia to improve the understanding and management of ASD. First, professionals should be aware that families of children with ASD have misinformation regarding ASD, use no evidence-based treatments, experience difficulties accessing ASD services, and suffer mental health issues. Thus, these results are essential for ASD diagnostic providers to co-develop their services to support families of children with ASD. Because providing information regarding ASD in quality and time is decisive in understanding their children’s disorder, dealing with ASD symptoms, and enabling them to use ASD resources. More importantly, providing families of children with ASD with accurate information regarding ASD can reduce their emotional issues, such as shame, guilt, and social isolation related to parenting children with ASD. Further, consultation and coordination services for families during the diagnostic process can overcome parental stress related to difficulties accessing services and help families to receive ASD services for their children with ASD. Therefore, future researchers may focus on families

of children with ASD who are newly diagnosed to overcome some emotional problems and develop an upskill for them to support their children's needs.

Increasing evidence-based ASD research in the context of Saudi society is an essential next step for professionals in the field of ASD. Researchers can adapt and modify the most effective evidence-based interventions for Saudi culture to support families and their children with ASD. Further, professionals working within the greater area of a rural or remote area could collaborate with other professionals worldwide, and some provide theoretical training. In contrast, those in a large metropolitan area closest to such rural areas could make site visits to ensure combining both online and in-person training for families to access evidence-based interventions. Government involvement in any country could be of great help. Therefore, exploring government agencies could facilitate the development of such programmes to provide funding, transportation, and accommodations for professionals. Relocating professionals for a specific period to train teachers or families in those areas to maximise the benefit and provide ASD services in rural and remote areas is imperative. Universities and colleges in such areas could also be involved to further assist in collaborating with other major universities in the country or worldwide to provide formal training for individuals from those communities interested in such training.

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Appendices

Appendix A

Ethics Approval Form

17-Jul-2020

Name:
Department/School: School of Education
Email: Cindy.Smith1@curtin.edu.au

Dear Cindy Smith

RE: Ethics approval
Approval number: HRE2020-0386

Cindy Smith

Thank you for submitting your application to the Human Research Ethics Office for the project **The Development and Evaluation of a Culturally Appropriate Home-Based Intervention for Children with Autism Spectrum Disorders in the Kingdom of Saudi Arabia**.

Your application was reviewed by the Curtin University Human Research Ethics Committee at their meeting on **04-Feb-2020**.

The review outcome is: **Approved**.

Your proposal meets the requirements described in National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2007).

Approval is granted for a period of one year, from **17-Jul-2020** to **16-Jul-2021**. Continuation of approval will be granted on an annual basis following the submission of an annual report.

Personnel authorised to work on this project:

Standard conditions of approval

1. Research must be conducted according to the approved proposal.
2. Report in a timely manner anything that might warrant a review of ethical approval of the project, including proposed changes to the approved proposal or conduct of the study unanticipated problems that might affect the continued ethical acceptability of the project,

major deviations from the approved proposal and/or regulatory guidelines
serious adverse events.

3. Amendments to the proposal must be approved by the Human Research Ethics Office before they are implemented (except where an amendment is undertaken to eliminate an immediate risk to participants).
4. An annual progress report must be submitted to the Human Research Ethics Office on or before the anniversary of approval, and a completion report submitted on the completion of the project.
5. Personnel working on this project must be adequately qualified by education, training, and experience for their role or supervised.

Research Office at Curtin

GPO Box U1987
Perth Western Australia 6845

Telephone +61 8 9266 7863 **Facsimile** +61 8 9266 3793 **Web** research.curtin.edu.au

Name	Role
Smith, Cindy	CI
Alanazi, Hissah	Student
Morrison, Chad	Co-Inv

6. Personnel must disclose any actual or potential conflicts of interest, including any financial or other interest or affiliation, that bears on this project.
7. Changes to personnel working on this project must be reported to the Human Research Ethics Office.

   8. Data and primary materials must be retained and stored in accordance with the Western Australian University Sector Disposal Authority.
8. (WAUSDA) and the Curtin University Research Data and Primary Materials policy
9. Where practicable, the results of the research should be made available to the research participants in a timely and clear manner.
10. Unless prohibited by contractual obligations, the results of the research should be disseminated in a manner that will allow public scrutiny; the Human Research Ethics Office must be informed of any constraints on publication.
11. Ethics approval is dependent upon ongoing compliance of the research with the Australian Code for the Responsible Conduct of Research, the National Statement on Ethical Conduct in Human Research, applicable legal requirements, and with Curtin University policies, procedures, and governance requirements.
12. The Human Research Ethics Office may conduct audits on a portion of approved projects.

Special Conditions of Approval

It is the responsibility of the Chief Investigator to ensure that any activity undertaken under this project adheres to the latest available advice from the Government or the University regarding COVID-19.

This letter constitutes ethical approval only. This project may not proceed until you have met all of the Curtin University research governance requirements.

Should you have any queries regarding the consideration of your project, please contact the Ethics Support Officer for your faculty or the Ethics Office at hrec@curtin.edu.au or on 9266 2784.

Yours sincerely

Associate Professor Sharyn Burns
Chair, Human Research Ethics Committee

Appendix B

Consent Form for Parents

HREC Project Number:	TBA
Project Title:	The Development and Evaluation of a Culturally Appropriate Home-Based Intervention for Children with Autism Spectrum Disorders in the Kingdom of Saudi Arabia
Chief Investigator:	Dr. Cindy Smith
Student researcher:	Hissah Alanazi
Version Number:	**2**
Version Date:	**20/03/2020**

- I have read the information statement version listed above, and I understand its contents.
- I believe I understand the purpose, extent, and possible risks of my involvement in this project.
- I voluntarily consent to take part in this research project, and I may withdraw at any time if I change my mind.
- I have had an opportunity to ask questions, and I am satisfied with the answers I have received.
- I understand that this project has been approved by Curtin University Human Research Ethics Committee and will be carried out in line with the National Statement on Ethical Conduct in Human Research (2007).
- I will receive a copy of the Information Statement and Consent Form.

Participant Name	
Participant Signature	
Postal Address	
Email Address	
Phone number	
Date	

Appendix C

الموافقة على المشاركة في البرنامج التدريبي

رقم البحث	
عنوان البحث	بناء وتقييم برنامج تدريبي مناسب ثقافياً للأطفال ذوي التوحد في المملكة العربية السعودية
المشرف الدراسي	د.سيندي سميث
الباحثة	حصة العنزي
رقم الإصدار	**HRE2020-0386**
تاريخ الإصدار	٢٠٢٠/٧/١٧

* لقد قرأت نسخة من المعلومات حول البحث المذكور أعلاه وأنا أفهم محتواها.
*أنا أفهم الهدف من البحث والمخاطر المحتملة لمشاركتي في هذا المشروع البحثي.
*أنا أتطوع في المشاركة في هذا المشروع البحثي، ويحق لي الانسحاب في أي وقت•
*لقد أتيحت لي الفرصة لطرح الأسئلة وأنا راضٍ عن الإجابات التي تلقيتها.
*أنا أفهم أن هذا المشروع قد تمت الموافقة عليه من قبل لجنة أخلاقيات الأبحاث البشرية بجامعة كيرتن وسيتم تنفيذه بما يتماشى مع البيان الوطني بشأن السلوك الأخلاقي في الأبحاث البشرية (٢٠٠٧).

الاسم	
التوقيع	
العنوان	
البريد الإلكتروني	
رقم الهاتف	
التاريخ	

تصريح من الباحثة: تلقى المشارك ونموذج موافقة ونسخة من المعلومات يصف الغرض من الدراسة والمخاطر المحتملة من المشاركة في هذا المشروع البحثي، من أجل اتخاذ القرار بشأن المشاركة.

اسم الباحثة	
توقيع الباحثة	
التاريخ	

ارجوا منكِ الاطلاع على الجمل التالية واختيار الإجابة التي تناسبك:
موافقة اختيارية:

☐ أوافق	☐ لا أوافق	الزيارة المنزلية بغرض تنفيذ الجزء النظري من البرنامج التدريبي

☐ أوافق	☐ لا أوافق	استخدام بيانات التي تم جمعها قبل الانسحاب من الدراسة

☐ أوافق	☐ لا أوافق	التسجيل الصوتي للمقابلة الشخصية