Universitätsklinik für Psychiatrie und Psychotherapie Tübingen
Abteilung Allgemeine Psychiatrie und Psychotherapie mit Poliklinik

Diagnostic and intervention care model for autism spectrum disorder in Rwanda

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Dean: Professor Dr. B. Pichler

1. reviewer: Professor Dr. T. Renner
2. reviewer: Professorin Dr. C. Mahler

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DEDICATION

My late parents, Sekalyongo Felicien and Kankindi Veronique, are honored in this dissertation for their unwavering support, education, and guidance. This work is also dedicated to my wife, Mrs. Bankundiye Mechtilde, my sons, Rukundo Baziga Irene Serge and Hirwa Baziga Emerry, as well as my daughter, Uwurukundo Baziga Mireille, for their help, understanding, and patience throughout my academic career.

Table of contents

List of tables 1

List of figures 2

List of abbreviations 3

CHAPTER I: GENERAL INTRODUCTION 6

1.1. Theoretical background 6

1.1.1. Autism spectrum disorder 6

1.1.2. ASD assessment methods 19

1.1.3. Interventions for ASD 22

1.2. History of psychiatric care in Rwanda 27

1.3. Decentralization of psychiatric services in PHC facilities 29

1.5. Problem statement 31

1.6. General overview of the present dissertation, purpose and the general research question 32

1.7. Rationale of the present study 33

CHAPTER II: ASSESSMENT OF ASD SYMPTOMS IN FAMILY CONTEXT IN RWANDA 36

2.1. Introduction and background 36

2.2. The study aims 40

2.3. Research hypothesis for the study one 41

2.4. Materials and Methods 41

2.4.1. Research setting 41

2.4.2. Research population 42

2.4.3. Sampling, recruitment and design 43

2.4.4. Structure, protocol of the study 44

2.4.5. Tools for data collection 44

2.4.6. Calculations and statistical analysis 50

2.4.7. Data management 51

2.4.8. Ethical considerations 52

2.5. Results 53
2.5.1. Research participants' characteristics 53
2.5.2. Difference between means scores of groups of socio-demographic characteristics achieved CARS-2 and CASD. 58
2.5.3. Reliability and concurrent validity 61
2.5.3. Correlation between CARS2 and CASD total scores 62
2.6.1. Difference between means scores of groups of socio-demographic characteristics achieved CARS-2 and CASD. 63
2.6.3. Reliability, concurrent validity and correlation between 2 measures for ASD (CARS-2 and CASD) 67
2.7. Conclusion 68
2.8. Limitations 69
CHAPTER III: CHALLENGES AND COPING STRATEGIES OF PARENTS AND CLINICIANS CARING CHILDREN WITH ASD IN RWANDA 70
3.1. Introduction and background 70
3.2. Study aims 72
3.3: Methods and materials 73
3.3.1. Research setting & participants 73
3.3.2. Research approach and design 74
3.3.3. Data collection and materials 74
3.3.4. Data analysis 74
3.3.5. Trustworthiness: 75
3.4. Findings 76
3.5. Discussion 86
3.6. Conclusion 90
3.7. Limitations 90
CHAPTER IV: A PILOT AND FEASIBILITY RANDOMIZED CONTROLLED TRIAL OF FAMILY FOCUSED TRAINING THERAPEUTIC MODEL FOR ASD IN SSA (FASSA) 92
4.1. Introduction and background 92

4.2. Aims of the study 95
4.3. Hypothesis for study 3 (chapter IV) 96
4.4. Materials and Methods 97
  4.4.1. Research setting 97
  4.4.2. Research population 97
  4.4.3. Sampling 98
  4.4.4. Procedure and Design 99
  4.4.5. Structure and protocol of the study 103
  4.4.6. Blinded outcome assessment 104
  4.4.7. Instruments for data collection 104
4.5. Results 117
  4.5.1. Description of participants at baseline assessment 117
  4.5.2. Other services used along with the study intervention (TAU) 119
  4.5.3. Feasibility for the study 120
  4.5.4. Reduction of ASD symptoms 124
4.6. Discussion 129
  4.6.1. Feasibility of the study 129
  4.6.2. Reduction in ASD of ASD symptoms from baseline to 24 weeks 131
4.7. Conclusion 132
4.8. Limitations 133
CHAPTER V: GENERAL DISCUSSION 134
5.1. Discussion 134
5.2. Conclusion 136
5.3. Overall strengths and limitations 138
5.4. Implication for research and practice 139
CHAPTER VI. SUMMARY OF THE STUDY 141
6.1. Summary of the Study (English version) 141
6.2. Summary of the study (German version) 144

VII. BIBLIOGRAPHY 148

APPENDICES 171

List of tables

Table 1: DSM-5 and ICD-10 Diagnostic Criteria for ASD 9

Table 2: Samples of the ASD diagnostic instruments........ 21

Table 3: Description of study characteristics and effectiveness of non-specialist and specialist interventions for ASD 25

Table 4 : Research questions for the study 1 (Assessment of ASD symptoms in family context in Rwanda) 39

Table 5: Descriptive statistics of the sample (Children with ASD) 54

Table 6: Descriptive statistics of the sample (mothers to children with ASD) 56

Table 7: Difference between means scores of groups of socio-demographic characteristics achieved CARS-2 and CASD: Children with ASD 59

Table 8: Difference between means scores of groups of socio-demographic characteristics achieved CARS-2 and CASD: Mothers of children with ASD 61

Table 9: Social demographic variables of parents and clinicians 73

Table 10.: Summarized list of hypotheses study three........ 96

Table 11:Comparison between the original intervention care model and the proposed adapted intervention care model........ 111

Table 12:Summary of intervention training sessions, topics and goals 115

Table 13: Baseline demographics of children with ASD........ 117

Table 14: Baseline demographics of the mother of children with ASD 119

Table 15: Comparison of intervention and control groups with regards of TAU 120

Table 16: Descriptive statistics of the session ratings (SRS)........ 123

Table 17: Descriptive statistics of the children outcomes (CORS)........ 124

Table 18: CARS-2 statistics scores for intervention group (FASSA with TAU) and control group (TAU only)........ 126

Table 19: CASD of statistics test scores for intervention group (FASSA with TAU) and control group (TAU only) across three time periods........ 127

List of figures

Figure 1: The flow chart of overview of the empirical studies for the present dissertation 33
Figure 2: The flow-chart of participant recruitment for the study 1 43
Figure 3: The translation process of research instruments 48
Figure 4:The flow diagram of the present study (Pilot and Feasibility parallel RCT) 102
Figure 5: The process of adaptation of Indian parent mediated intervention 109
Figure 6: Satisfaction of parents with regard to training sessions (SRS) 122
Figure 7: FASSA outcomes as measured using CORS 123
Figure 8: Reduction of ASD symptoms on CARS-2 scores from baseline to 24 weeks 125
Figure 9: Reduction of ASD symptoms on CASD scores from baseline to 24 weeks 127

List of abbreviations

ADHD: Attention Deficit and Hyperactivity Disorder

ADI-R: Autism Diagnostic Interview Revised

ADOS: Autism Diagnostic Observation Schedule

ANOVA: Analysis of Variance

APA: American Association of Psychiatry

ASD: Autism Spectrum Disorder

ASQ: Age and stages Questionnaire

CARS: Childhood Autism Rating Scale

CASD: Checklist for Autism Spectrum Disorder

CHUK: Centre Hospitalier Universitaire de Kigali

CMHSIRB: College of Medicine and Health Sciences Institutional Review Board

CORS: Child Outcome Rating Scale

CSBS: Communication and Symbolic Behavioral Scale

DSM-4: Diagnoses Statistical Manual version 4

DSM-5: Diagnoses Statistical Manual version 5

CwDs: Children with Disabilities

EAB: Expert Advisory Board

ENT: Ear, Nose and throat

EBP: Evidence Based Practice

FASSA: Family Focused Training therapeutic care model for autism spectrum disorder in Sub-Sahara Africa

HIC: High Income Countries

HIV/AIDS: Human Immunodeficiency Virus/ Acquired Immunodeficiency Syndrome

HFA: High Functioning Autism

HVP GATAGARA: Home de la vierge des pauvres de Gatagara

ICD: International Classification of Diseases

IQ: Intelligence Quotient

LIC: Low Income Countries

LAMIC: Low and middle income countries

M-CHAT: Modified Checklist for Autism in Toddler

MD: Mental disorders

NCST: National Council of Science and Technology

NDBIs: Naturalistic Developmentally Behavioral Interventions

NDD: Neurodevelopmental disorders

NHR: National Health Research

NISR: National Institute of Statistics of Rwanda

NGOs: Non-Government Organization

PI: Principal Investigator

PHC: Primary Health Care

RGB: Rwanda Governance Board

RNEC: Rwanda National Ethics Committee

SDG: Sustainable Development Goals

SRS: Session Rating Scale

SSA: Sub-Sahara Africa

STAT: Screening tool for Autism in Toddler and Young Children

TAU: Treatment as usual

ToM: Theory of Mind

UK: United Kingdom

USA: United States of America

WHO: World Health Organization

CHAPTER I: GENERAL INTRODUCTION

ASD is a common neurodevelopmental disorder whose onset is in the developmental period of 2 - 3 years. ASD is evidenced by abnormal reciprocity or interactive communication, stereotypical behavior, and activities interfering with life routines (American Pyschiatric Association [APA], 2013). Thus identification of ASD is based on behavioral/ clinical manifestation as described by parents to children with ASD and health professionals' observation than physiological or psychological features (Lebersfeld, Swanson, Clesi & Kelley, 2021). Moreover, on top of behavioral clinical manifestation, parents report different challenges in family routine activities related to children ASD symptoms (Reddy, Fewster & Gurayah, 2019).

Recently, researchers have been investigating ASD etiological, psychological and physiological features (Bölte, Girdler & Marschik, 2019; Yoon, Choi, Lee & Do, 2020). Assessment methods have been developed and tested internationally, as evidenced by several ASD assessment instruments now in place (National Institute for Health Care & Excellence [NICE], 2012; Mandell, Stahmer & Brodkin, 2011). These have been used for early ASD identification which in turn inform early intervention, leading to positive impacts on ASD symptoms outcomes (Alonso-Esteban & Alcantud-Marín, 2022; Naveed et al., 2019). The present dissertation consists of five chapters as follows; chapter I describes general introduction; chapter II describes ASD symptoms assessed in family context; chapter III describes challenges and coping strategies of parents and clinicians caring children with ASD; chapter IV describes a pilot and feasibility randomized controlled trial of family focused training therapeutic model for ASD in SSA (FASSA). Chapter V is comprised of the general discussion covering conclusion, overall strengths, limitation and implication for practice and research.

1.1. Theoretical background

1.1.1. Autism spectrum disorder

1.1.1.1. Symptoms and etiology of ASD

Description of ASD symptoms founded on the official international diagnostic manuals that describes in detail the mental disorders and behavioral disorders including ASD. The official international diagnostic manuals is inclusive of the ICD version 10 initiated by the World Health Organization (World Health Organization [WHO], 1997; Quaschner, 2010) and the diagnostic statistical manual version 5 (DSM -5) that focuses on system of classification for mental illnesses as developed by the American Psychiatric Association (APA, 2013; Gulati et al., 2019). Both the ICD-10 and DSM-5, are commonly employed for both research and clinical purposes. The criteria in diagnosing ASD, is applied in the following sections, and together with the two international standardized instruments considered as the references for the diagnostic process.

Characteristics of ASD according to DSM-5

The DSM version five is the manual published in 2013, and in use. Autism is deliberated throughout the chapter on neurodevelopmental disorders (APA, 2013). According to APA, people with diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder, not otherwise specified, are expected to undertake the diagnostic process for autism (APA, 2013; Gulati et al., 2019). Thus, ASD includes all mental disorders that were considered to be early infantile autism, childhood autism, Kenner's autism, high-functioning autism, atypical autism, pervasive developmental disorder not otherwise specified, childhood disintegrative disorder, and Asperger's disorder (APA, 2013; Gulati et al., 2019). APA accentuated that the diagnosis of ASD can be carried out using such criteria as; (A) persevering deficiency for communicating and interacting with others found in different settings exhibited either presently or in the past: (B) constricted and repetitive unusual behavior, interests, or activities exhibited either currently or in the past: (C) symptoms should start in first phases of child development: (D) symptoms that, cause important dysfunctional social, occupational, or other main domains and: (E) disruptive symptomatology should not be due to intellectual disability or general developmental problem (APA, 2013; Gulati et al., 2019). The ASD diagnosis can be specified or made with or without the presence of altered intellectual aspect or altered speech, linked to another somatic condition, mental or behavioral disorder and catatonia

Characteristics of ASD according to ICD -10

In the ICD-10, the ASD is classified under pervasive developmental disorders (F80.0-F80.10) and has onset in childhood. The severity of ASD condition varies from one to another and it is detected before 5 years of human development (WHO, 1997).

The ICD-10 consistently highlights deficits in exchange social interaction that characterize the childhood autism and considered as inappropriate esteem of socio-emotional sign, evidenced by; (a) inability to consider other persons' emotions or :(b) inability to control behavior consistent with the present social context: (c) poor utilization of nonverbal communication: (d) inadequate socio-emotional integration, and communication skills; (e) inadequate socio-emotional exchange. In addition, deficits in communications are repeatedly seen. Impairments in communication include poor utilization of social signals as communication/ language skills, inability in imitating others, lack of interchange in conversation with others, absence of flexibility in self-expression and poor skills in creative thinking and deficiencies in emotional reaction or responses to others seen in poor use of gestures to communicate with others (WHO, 1997; Quaschner, 2010).The table 1 displays DSM 5 and ICD 10 diagnostic criteria for ASD .

Table 1**:** *DSM-5 and ICD-10 Diagnostic Criteria for ASD*

DSM-5	**ICD-10**
A. Persistent deficits in social communication and social interaction across multiple contexts	A. Abnormal or impaired development is evident before the age of 3 years in at least one of the following:
1. Deficits in social-emotional reciprocity, ranging	1. receptive or expressive language as used in social communication
2. Deficits in nonverbal communicative behaviors used for social interaction, ranging	2. the development of selective social attachments or of reciprocal social interaction
3. Deficits in developing, maintaining, and understanding relationships, ranging	3. functional or symbolic play
B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following	B. A total of at least 6 symptoms from (1), (2), and (3) must be present, with at least two from (1) and at least one from each of (2) and (3):
1. Stereotyped or repetitive motor movements, use of objects, or speech	1. Qualitative abnormalities in reciprocal social interaction are manifest in at least two of the following areas:
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior	(a) Failure adequately to use eye to eye gaze, facial expression, body posture, and gesture to regulate social interaction
3. Highly restricted, fixated interests that are abnormal in intensity or focus	(b)failure to develop peer relationships that involve a mutual sharing of interests, activities, and emotions
4. Hyper- or hypo reactivity to sensory input or unusual interest in sensory aspects of the environment	(c) lack of social emotional reciprocity

Table 1: *DSM-5 and ICD-10 Diagnostic Criteria for ASD (continued)*

C. Symptoms must be present in the early developmental period	(d) lack of spontaneous seeking to share enjoyment, interests, or achievement with other people
D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning E. These disturbances are not better explained by intellectual disability **DSM-5**	2. Qualitative abnormalities in communication are manifest in at least one of the following areas: (a) a delay in, or total lack of, development of spoken language **ICD-10** (b) relative failure to initiate or sustain conversational interchange (c) stereotyped and repetitive use of language or idiosyncratic use of words or phrases (3) Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities are manifest in at least one of the following areas: (a) an encompassing preoccupation with one or more stereotyped and restricted pattern of interests (b) apparently compulsive adherence to specific, no functional routines or rituals (c) stereotyped and repetitive motor mannerisms that involve either hand or finger flapping or twisting, or complex whole body movements (d) preoccupations with part objects or non- functional elements or plays materials C. The clinical picture is not attributable to other varieties of pervasive developmental disorders

Prevalence of ASD

The prevalence of ASD varies worldwide, across continents and countries, whether high, middle and low income countries. ASD global prevalence is ranging between 0,09% and 3.13% (APA, 2013; Zeidan et al., 2022). However, it is unknown as to whether increased prevalence indicate an expansion of criteria for diagnosis in DSM-5. The relative high rates of ASD can be due to increased awareness, problems with the study methods, or real increase of ASD frequency (Chauhan et al., 2019; Hidalgo et al., 2021; Imm et al., 2019; Shuang et al.,2020; Wang et al., 2018; Zeidan et al., 2022; Zhou et al., 2020). However, rates vary, indicating the insinuation of socio-demographic factors, global public health response, community awareness and service capacity factors (Zeidan et al., 2022). Some countries are reported to have lower prevalence of ASD due to the under diagnosis (Wang et al., 2018).

Coming to Africa, in Nigeria, the prevalence was calculated using clinical settings data. Researchers reported 2.3 % and 1.4 %, respectively as the prevalence of ASD (Lagunju et al., 2014). The school population was used to estimate the prevalence in Nigeria, the prevalence among primary school pupils and secondary school students of 2.9 % (Lagunju et al., 2014), while Essien, Akpan, and Ekanem, estimated prevalence of 1.1 % for preschooler and scholar children (Paulinus Umoren Essien, Mkpouto Udeme Akpan, 2017). For children suffering from developmental disorders, Bakare, Ebigbo, and Ubochi presented relatively high estimated rates of prevalence of 11.4 %) (Bakare et al., 2022), while Oshodi and colleagues displayed rates of 34.5 % among children with developmental disorders in community setting (Oshodi et al., 2017).

In Mali, 2 studies reported the prevalence of ASD (Traore, Coulibaly & Temely, 2018). The highest prevalence rate presented by Traore, Coulibaly andTemely in children who consulted hospitals was 7.8 %. Although widely-recognized in developed nations with experts available, awareness and knowledge about ASD is low in developing countries and community-based epidemiological studies and state-of-the-art diagnostics of ASD are still scarce in SSA (Bakare et al., 2019; Ruparelia et al., 2016). Currently, Rwanda and most SSA countries miss national estimates of ASD prevalence, except Mali and Nigeria (Chinawa et al., 2016; Traore, Coulibaly,Temely, 2018). The ongoing debates suggest that limited knowledge on the clinical phenotypes across the autism spectrum sometimes makes it difficult to distinguish it from other mental impairments. Thus, it becomes very difficult to diagnose ASD cases and provide early intervention. There is limited knowledge on economic burdens affecting families of autistic children in Africa, as cited in one study from Egypt (Mendoza, 2010) and another study in South Africa (Erasmus et al., 2019). Considering the limited information about ASD, the prevalence is unknown in Rwanda.

Development and course of the ASD symptoms

The ASD is one of neurodevelopmental disorder whose onset is in the earlier developmental period of 2 and 3. Therefore, an important question is whether symptoms of ASD persist until the adulthood. Current literature highlights that ASD is a disorder which often persists into adulthood (Legg et al., 2022; Nyrenius, Eberhard, Ghaziuddin, 2022; Rosello et al., 2021) However, the prevalence rate for children is higher than those for adults (Nyrenius, Eberhard, Ghaziuddin, 2022). This indicates that a number of people meeting the criteria of ASD during the childhood do not necessary correspond with criteria for ASD as adults. The persistence of ASD symptoms until adulthood may be related to unfavorable psychosocial conditions, other impairments related to ASD and some comorbidities (Legg et al., 2022). Moreover, awareness of ASD diagnosis can improve changes in roles, communication, interactions and as well relationships (Legg et al., 2022).

From childhood through adulthood, ASD is a condition that can last a lifetime. However, most ASD sufferers do better with age, although fewer suffer from behavioral deterioration in adolescence in children with ASD. (APA, 2013). Only fewer people with ASD perform effectively in their routines when they become adults (APA, 2013). However, there is dearth of information about the ASD in old age and the significant impairments socially, occupationally, and sufficient persistence of symptoms (APA, 2013). For ASD diagnosis, WHO suggests that the symptoms should have been existing before age 3, even if the diagnosis can be made during different stage of life. The ICD-10, also explains that as the child grows, specific characteristics of ASD may change whilst the different deficits in communication socialization and interest may persist until adulthood (WHO, 1997; Quaschner, 2010)

Etiology of ASD

Theories of causation in the development of ASD take into account different perspectives, namely; the neurobiological (including genetics), psychological and environmental perspectives

(Rylaarsdam & Guemez-Gamboa, 2019). However, a psychopathological basis of the ASD condition is unclear or even unknown (Bölte, Girdler & Peter, 2019; Mahic et al., 2017). The associated factors include perinatal risks, diet, vaccination, medications, parental age, teratogenicity, smoking and alcohol consumption, toxic exposures, and the role of extreme psychosocial factors (Bölte et al., 2019; Nardone & Elliott, 2016; Yoon et al., 2020). Previous studies demonstrate increased ASD vulnerability in; exposure to toxic chemicals, maternal diabetes, increased steroidogenic activity, advanced maternal and paternal age, valproate use, body's immune response and compromised zinc-copper cycle as well as management with selective serotonin reuptake inhibitors (Bölte et al., 2019; Mahic et al., 2017; Nardone & Elliott, 2016). Studies suggesting that autism is mostly inherited and that genetic risk factors involved in brain development, semantic network and social interactions, offer crucial evidences in describing the cause of ASD (Yoon et al., 2020). The authors propose specific genetic factors, like alteration of histone, methylation of DNA, and non-coding RNA, in contributing towards ASD development (Yoon et al., 2020). The recommended future researches should also aim to clarify the contribution of environmental effects to ASD, such as gene and environment interactions employing twin studies, longitudinal and experimental models (Bölte et al., 2019).

The heritability, discussed in the DSM 5 as well, emphasizes that heritability estimates for ASD reach 90% based on twin concordance rates. Fifteen percent (15%) of ASD cases seem to be related to gene mutation, with distinct de novo copy number mutations in particular genetics related with the disorder in varied families (APA, 2013; Gulati et al., 2019). The neurological theory states that the abnormal cerebral actions and unusual brain morphology during childhood seem to underline the manifestation of ASD symptoms as indicated in different studies. Findings reveal that abnormal brain development of ASD occurs during a critical developmental period at a time when creation and wiring of brain pathways are at their uttermost and when synaptic actions are as its peak. Thus, abnormal cerebral development hinders cerebral development connectivity, necessary for the operation of optimal neural pathways, a process that might lead to autism condition (Boersma et al., 2013).

A typical cerebral overgrowth and the abnormal brain excess growth was observed in the brains of preschooler Children with ASD in their first and second years of life, specifically in the cerebellar, cerebral, and limbic regions (Courchesne et al., 2011). These areas control the process and the utilization of language use, social, cognitive, pragmatic and emotional functions which are impaired on the part of ASD population. In conclusion, the neurobiological side of ASD patients exhibits a variety of anomalies in the genome and in brain structure and physiology. However, these results do not provide a conclusive picture and other research would be recommended to clarify implication of neurobiological influence on ASD development.

Furthermore, Theory of Mind (ToM) is not left behind in understanding the major symptoms of ASD. The everyday social life of children with ASD is influenced by their ability to evaluate and understand other people's behavior as well as their goals, emotions, desires, intentions and beliefs (Peterson, Virginia, Chris & Wellman, 2016; Tager-Flusberg, 2007). The mental states also engross the cognitive systems referred to as the theory of the mind but ASD is defined as the absence of the theory of the mind (Tager-Flusberg, 2007). Considering the neurodevelopmental perspective, the mental states that assists a child to understand the real world behavior starts at the age of 4, as children perform false belief tasks (Tager-Flusberg, 2007). The theory of mind may be used in describing and explaining the major behavioral symptoms characterizing the ASD, which are impairments of reciprocal social interaction and communication (Peterson et al., 2016). These symptoms are the result of cognitive mechanisms underlying core behavioral features that define the disorder, perceived as difficulties in mental states of themselves and other people. Thus, children with ASD have problems in processing mental state information that governs human actions, like to initiate, sustain interactions with others, communicate relevant information and cooperate with others in family, school, or community settings (Peterson et al., 2016; Tager-Flusberg, 2007)

Only few researches have investigated whether the core ASD symptom are directly linked to impairment theory of mind or not. Other studies have revealed correlations between social communication and the theory of mind performance, but such correlations became insignificant when the child age and language level were considered as control variables (Peterson et al., 2016; Tager-Flusberg, 2003). However, these findings were criticized as having a small sample size. The theory of mind scores was significantly correlated with scores on the socialization domain, measured by Vineland Adaptive Behavior Scales, and social- and communication-symptom severity, measured on the Autism Diagnostic Observation Schedule. Recently, this issue was addressed by using larger samples of school-aged children with ASD. (Tager-Flusberg, 2003). As described in DSM 5, all children with ASD have serious difficulties in reciprocal social interactions and communicative skills that are said to impact the children's routines in interacting with others in the family, school or community settings. As a result, the degree of theory of mind impairments would have an impact on the diversity in the severity of social and communicative deficits (Peterson et al., 2016).

1.1.1.2. Diagnostic process

The ASD diagnosis is made and confirmed once impairment is observed in every day functioning. Current literature emphasises that the ASD diagnosis is made, taking into consideration the three important components, which are, child development, symptoms observation and clinical confirmation (Constantino & Charman, 2016). The diagnostic process begins when family members and clinicians realize warning signs of ASD and a confirmation of the warning signs by clinicians involves use of the international standardised tools (Alonso-Esteban & Alcantud-Marin, 2022).

The screening and diagnostic instruments in use were developed in the western countries. There were then adopted, and adapted in the different worldwide countries including Asian and African countries. Social factors were considered during the procedure of ASD diagnosis as guided by clinical guidelines (Hayes, Ford, Rafeeque & Russell, 2018).-DSM-5 recommends that the details on child behaviour to inform appropriate diagnosis are provided by clinician, parent or any other caregiver and client (if applicable).

Current literature also suggests many other areas to be considered when conducting an ASD assessment provided in the UK national guidelines which delivers more details on that (Hayes et al., 2018). The UK national guidelines emphasize the use of documentary evidence, risks and challenging behaviors as other areas that need consideration when performing the ASD assessment. The challenging behaviors to be assessed include comorbidities, somatic evaluation, and assessment of various domains dysfunction (Hayes et al., 2018; Royal College of Psychiatrists, 2018). Again, guidelines for professionals recommend other factors to be included in the assessment of ASD, such as cognitive evaluation and mental health evaluation as well as relationships in various settings and observation where the child lives or performs daily activities (Hayes et al., 2018; Royal College of Psychiatrists, 2018).

These guidelines also emphasize that community practitioners should take part in referral process other than being only involved in diagnostic process (Reynolds & Malow, 2011) and that assessment should focus on co-occurring conditions including somatic clinical evaluation (Blenner, Reddy & Augustyn, 2011; Carpenter, 2012; Wilson et al., 2014). Lastly, its related coping capabilities are to be considered in the assessments elements. (Blenner et al., 2011).

International standardized diagnostic procedures include the German AWMF diagnostic guidelines (German Society & Psychiatry and Psychotherapy [DGPPN], 2016) and the British NICE guidelines (British Psychological Society, 2021). The methods for ASD diagnosis proposed by Health care associations are as follows; organic examination, neuropsychological tests, behavioral observation, clinical exploration and questionnaires (Scottish Intercollegiate Guidelines Network [SIGN], 2016; Royal College of Psychiatrists, 2018).

For *clinical evaluation*, health professionals interview a parent with ASD child. Interview focuses on the ASD symptoms, severity of symptoms, regularity, and symptoms changes or improvement, comorbidities and problems related to psychosocial patterns. Clients (children, adolescents or adults) may report and describe the ASD features/ symptoms themselves if applicable. The interviews used may be unstructured and structured aiming at clinical explorations. Clinical explorations are usually unstructured allowing parents to express themselves. In clinical setting clinicians may conduct the structured interviews for assessment purposes, but the interviews do not interest clinicians frequently (Nilsson & Nylander, 2019).

Standardized questionnaires/ instruments, may add on data gathered during clinical assessment. The data on ASD symptoms given by parents, caregivers or teachers should be used to augment the clinical observations by health professionals. However, information obtained via self-report instruments/ questionnaires may be considered on Children with ASD with at least the age of 11 (Constantino, Davis, 2012; Schopler; Jay; Reichler & Rochen, 1992). The reports of information given by children are non- informative as of teachers and parent reports. Also, parents complete specific questionnaires like checklists and generally gather information on the children psychopathology (Heiervang, Achenbach, Becker & Döpfner, 2008).

Neuropsychological tests focus on the assessment of intelligence level, attention, cognition, speech abilities, body movement, and functioning abilities during the diagnostic process. According to Heiervang and colleagues (2008), the neuropsychological tests can inform about the client cognitive functioning but precision is not sufficient to identify people with ASD.

However, intelligence tests that give opportunity to observe the child behavior and ASD symptoms can be used to test the child abilities for schooling.

The *neuropsychological tests*, add on information collected for diagnosis purposes. This clarifies the connection of ASD features with various different features in regards to neuropsychological functions that are very important to inform the differential diagnosis and the treatment plan (Braconnier & Siper, 2021). These authors recommended the use of neuropsychological evaluation to make differential diagnosis with comorbidities including mainly those that need to be diagnosed using standardized tools for appropriate diagnosis. Moreover, the neuropsychological assessments are taken with important considerations for monitoring the progress of school performance, occupation and adaptive targets (Braconnier & Siper, 2021).

The study conducted on people suffering from ASD (adults), revealed poor entire neuropsychological assessments among persons suffering from autism, suggesting deficiencies in neuropsychological functions (Haigh , Keller, Minshew & Eack, 2020). These findings indicate that the tracts that are the more affected in ASD would not be the direct cause of behavior deficits among people with ASD (Haigh et al., 2020). Another study suggested significant executive functions complications (Grove, Ripke, Als, 2019; Patrick et al., 2020)

Organic examinations can be conducted for differential diagnostic purposes, such as neurologic evaluations needed to find out somatic problems which can cause the same symptoms as those for ASD like epileptic condition. A study conducted to investigate functional constipation revealed a functional constipation as common in population with ASD (Civan, Ayyıldız, Semra & Didem, 2021). However, somatic symptoms cannot be considered in the identification of ASD condition.

Behavior observation of ASD symptoms is commonly performed when the clinical exploration, neuropsychological assessments and somatic evaluations are in progress (Civan et al., 2021). Unfortunately, ASD symptoms are seen to be reduced in various contexts as during assessments and in the consultation rooms for clinicians in health settings (Civan et al., 2021). However, the absence of pertinent ASD symptoms is not indicative of the absence of observed symptoms during evaluations. Observations in natural environment are frequently not feasible, but are preferred and recommended by the guidelines for ASD diagnosis (Berger et al., 2022).

Thus, if possible the video-recorded behavioral observations in meaningful situations or any other digital materials (dinner, homework, play) in natural environments are advised (Berger et al., 2022; Berger et al., 2020).

The third party history (parents to children with ASD, teachers) and validated assessment instruments were recommended by professional associations in obtaining data of ASD symptoms while children behavioral observation was reported by the official guidelines, without important consideration. The assessment techniques or approaches allow collection of information on ASD and are different in quality and nature. For example, the clinician observation of ASD symptoms does not give the same quality and nature of information gathered via parent experience expressed by during clinician observation. However, it is recommended to combine all of these methods to obtain sufficient quality and nature information (Berger et al., 2022).

Distinction made between persons with and without ASD

In clinical practice, clinicians meet several people who complain of behavioral and emotional related symptoms. People with ASD may present their symptoms by themselves or any closer kin of their like parents may present behavioral disturbances on their behalf. Then, clinicians should be in a position to differentiate a person with ASD from the one who is free of ASD. The answer is clearly found in current literature, which offers the criteria on how to make a conclusion on the presence or absence of ASD (APA, 2013; WHO, 1997; Quaschner, 2010). As mentioned in the table 1 and 2, APA proposes that the ASD characteristics can appear during the earlier developmental stage, before age 3. Also, the ASD characteristics might be manifested only once the capacities of the person is inferior compared to person with social demands that are higher than or simply can be hidden by acquired/ learned strategies/ skills in future life.

According to APA, clinical significant impairments such as social, occupational, and other domains of life functioning are to be considered for ASD diagnosis as described on Criteria D (APA, 2013). The WHO indicates that, to make a conclusion of ASD, the client should have at least symptoms ranging from 1 to 6 symptoms respectively (WHO, 1997; Quaschner, 2010). Common international standardized instruments for ASD assessment propose cut-offs for deciding the ASD diagnosis. For example, childhood autism rating scale version 2 (CARS2) gives opportunity to clinicians and researchers to categories. ASD three categories is based on scores achieved on the scale (Moulton, Bradbury & Barton, 2019). These categories include mild (30-36 score), moderate (37-45 score) and severe ASD (45-60 score). The assessed individual is considered to be undiagnosed with ASD when the score achieved is less than 30 (Moulton et al., 2019). Checklist for autism spectrum disorder (CASD) provide a cut - off to conduct ASD diagnosis (Mayes, 2012). Here, a client is equal to 16 or more achieved on CASD; while the possible maximum of scores is 30 (Mayes, 2012). According to these authors (APA, 2013; Mayes, 2012; WHO, 1997; Quaschner, 2010), certain individuals may have features of ASD but without fulfilling or meeting criteria of ASD or achieving the level or degree to be diagnosed with ASD. Based on results from the evaluation tool, which range from fewer to more symptoms and are categorized into different ranges, any individual may receive an ASD diagnosis. (Moulton et al.,2019). Consistent with this, the ASD evaluation tools assess ASD features/ symptoms totally and define cut-off (APA, 2013; Mayes, 2012). Thus, the categorization for autism and no autism might be crucial for practice because clinicians need to be informed about persons who are in need of treatment. Moreover, the significance of ASD categories is more understandable upon considering different impairments associated with ASD symptom affecting clients in their routine life (Johnson et al., 2021). The intensity of ASD symptoms is correlated with psychosocial issues in daily life, which include cognitive, linguistic, behavioral, and adaptive dysfunction. (Mehling & Tasse, 2016). The association between impairments and clinical symptoms of ASD is evident in academic achievement and or family or social relationships (Johnson et al., 2021).

In conclusion, as presented in the present and available ASD evaluation manuals, the ASD symptoms is based on behavioral descriptions reported by clinicians and parents as well. Categorization for autism and no autism is crucial to instruct the clinicians on the management needs.

1.1.2. ASD assessment methods

The previous sections of the background of the present thesis elaborated on ASD symptoms, etiological factors and the diagnostic procedures. This section discusses assessment methods used to obtain information for making ASD diagnosis, based on ASD symptoms reported and at cognitive and neurobiological level. Again, this section discusses how the assessment methods are different from one another. Although there are difficulties in early identification of ASD that lower its prevalence in developing countries, international scientists conducted studies to test validity and reliability of assessment tools for ASD (Hirota, So, Shin, Leventhal & Epstein, 2018; Lami, Egberts & Williams, 2017; Lebersfeld, Swanson, Clesi & Kelley, 2021). Literature suggests a growth in number of investigations concerning ASD that focus on the identification of ASD and has resulted in development and use of several screening and diagnostic tools (Hirota et al., 2018; Lami et al., 2017; Lebersfeld et al., 2021). The process in making a diagnosis begins when family members and clinicians realize warning signs of ASD and involves a confirmation of the warning signs by clinicians using the international standardised tools (Rosello et al., 2021).

Assessment of ASD symptoms is performed from reports which are based on ASD symptoms through the answers provided by a client, parent or another person (usually teacher report) (Hirota et al., 2018). These are the responses to the questions, showing how the explanation of ASD features/ symptoms complies with the ASD individual. Moreover, the items on standardized diagnostic instruments are based on criteria of ICD-10 or DSM-5 for autism condition.

The diagnostic and screening instruments have been developed mainly in west and were adopted and adapted in different worldwide countries including Asian and African countries. Most screening and diagnostic instruments were developed in USA. These instruments include, autism diagnosis observation schedule (ADOS 2) (Lebersfeld et al., 2021; Lord, Luyster, Gotham & Guthrie, 2014), autism diagnosis interview- revised (ADIR) (Oh, Song, Bong, Yoon, Kim, 2021) childhood autism rating scale (Moulton, Bradbury, Barton & Fein, 2019; Schopler; Jay; Reichler; Rochen, 1992) checklist for autism spectrum disorder (CASD) (Mayes, 2012), diagnostic statistical manual version 5 (DSM5) (Gulati et al., 2019; McPartland, Reichow, Volkmar, 2012) and social responsiveness scale (SRS) (Chan, Smith, Hong, Greenberg, Mailick, 2017; Chun, Bong, Han, Oh, Yoo., 2021). Moreover, recent literature provide some examples of screening tools as follows; parents' Evaluation of Developmental Status PEDS, Modified Checklist for Autism in Toddlers (MCHAT), ages and Stages Questionnaires (ASQ), Communication and Symbolic Behavior Scales (CSBS), Screening Tool for Autism in Toddlers and Young Children (STAT) (APA, 2013; de Bildt et al., 2015; Lami et al., 2017; Lamsal et al., 2018; Lord et al.,2014; Mattie & Hamrick, 2022; Moon, Hwang, Shin, Kim, 2019)

Multiple instruments should be used for ASD diagnostic process as the use of two or more instruments together improves diagnostic accuracy compared to each measure alone (Lebersfeld et al., 2021). Also, the evaluation must be based on parent-created descriptions that detail the child's growth or symptoms. Additionally, health professionals' observation while engaging in play with children is essential for the diagnosis process. (Lebersfeld et al., 2021; British Psychological Society, 2021). The information from parents'/ caregivers' description and professionals' observation is usually used to confirm the ASD diagnosis (Lord et al., 2014; Mayes, 2012; British psycholoval Society, 2021; Wilson et al., 2014). It is crucial to note that the professional observation of the child behavior as well as the caregiver observation and explanation of their children's developmental stages are needed as sources of information for ASD diagnosis (Lebersfeld et al., 2021; Lord et al, 2014).

The adapted and adopted international standardized tools have been translated into other languages to be used in different cultures. For example, ADI-R, which originally was developed in English version, was translated into German to fit in German culture (Poustka, Lisch, Rühl, Sacher, Schmötzer, Werner, 1996). Several studies have been-conducted internationally to test the correlation between the instruments developed by different scientists and they test accuracy of the ASD diagnostic instruments (Randall et al., 2018).

Table 2: *Samples of the ASD diagnostic instruments*

Measure	Author	sensitivity	Specificity	95% CI	Cut off
M-CHAT	QH et al., 2021	88.3%	36%		47.5
ADOS	Lebersfield et al., 2021	89-92%	81-85%		
ADI-R	OH et al., 2021	86-99.2%	84.7-99.5%		10
CARS	Moon, 2021	71-85%	75-79%	87-92%	30
DSM5	McPartland et al., 2012	46-67%	94.9%	92-97%	
SRS	Chun et al., 2021	78.1%	86.6%	14.08-17.24%	55
CASD	Mayes, 2012	100 %	100%		16

1.1.3. Interventions for ASD

In current literature, interventions conducted for HFA do not show whether there are differences between high functional autistic persons and other autistic children interfering with the impact of interventions (APA, 2013; Mckeithan & Sabornie, 2019; British Psychological Society, 2021). These interventions include early intervention programs, non-specialist programs and comprehensive ASD interventions.

Early intervention programs

The previous studies indicated improvement of ASD symptoms during the early intensive intervention programs for ASD (Penner, Rayar, Bashir, 2015). Also, these interventions mitigates burdens for the affected individuals and their caregivers, and is cost effective from an overall point of view (Penner et al., 2015). Literature suggests that early intervention is understood to be the period before school age, commencing between 2 and 3 years old (Horlin et al., 2014; Remington et al., 2007). Interventions that target the early childhood lead to favorable clinical improvement in autistic children. Current literature on Children with ASD, among different categories of people, upholds evidence-based practices (EBP) such as behavioral domain, human developmental domain, and education approaches to people with ASD. The literature displayed the outcomes related to changes in several domains as follows; communication, social capabilities, disruptive behaviors, school and play performances, pre-school and school skills, adaptive abilities, Joint attention , psychomotor abilities, cognitive function, and vocational abilities of people suffering from ASD condition (Su Maw & Haga, 2018). Furthermore, these authors discovered that the effect of such interventions towards the outcomes mentioned above, improves parent and child relationship and reduces stress affecting parents of autistic children (Naveed et al., 2019). Nevertheless, no exclusive intervention is globally successful in every child suffering from ASD and there is no standard and recommended treatment for ASD (Reichow et al., 2018; Su Maw & Haga, 2018).
Researchers have demonstrated that early diagnosis and intervention are likely to have significant long-term effects and outcomes on symptoms and skills of children with ASD, as was previously mentioned. ASD can be diagnosed before the age of 2 years old and some children with ASD start to regress during or before the 2 years old (Zwaigenbaum, Bauman, Choueiri, Kasari, Carter, Granpeesheh, 2015). Thus, early interventions start at or before preschool age before 2 or 3 years of age. The early intervention is very important and fruitful in improvement

of ASD symptoms because in this period (2 or 3 years old) a child's brain is still forming and developing (Zwaigenbaum et al, 2015). Also, in this period the brain is more plastic and changeable than at older ages. Due to such plasticity, therapeutic interventions have greater chance of being effective for long term. Along with possibility of best start, children with ASD have greater chances of developing potentials and skills. The earlier or sooner children receive assistance, the greater the change for learning new skills and progress in routines (Zwaigenbaum et. al., 2015). In deed current and recent guidelines confer starting developmental and behavioral therapeutic intervention as soon as possible after ASD is diagnosed or when it is extremely suspected (GDPPN, 2016; Hill et al., 2015; Royal College of Psychiatrists, 2018). Early intervention often includes family therapy, speech therapy, hearing impairment services, physical therapy and nutrition services as well (Zwaigenbaum et al., 2015). Primordial goals of early intervention are to help children to gain basic skills which are learnt in 2 years of life, such as physical skills, thinking skills, social skills, communication skills and emotional skills (Hill et al., 2015; Zwaigenbaum et. al., 2015).

Non-specialist interventions

Recently, non-specialists' interventions for a-ASD were initiated and implemented to reduce intensity of ASD features/ symptoms. These interventions are implemented on much less costs as required for interventions delivered by specialists professionals (Alcantud-Marín, 2022; National Autism Center, 2015; Reichow et al., 2018; Spain et al., 2017). Naveed and colleagues (2019) provide a proof for clinical and cost success for such interventions to ameliorate social, motor and communication deficiencies among the expected effects towards children with ASD. Moreover, non-specialist intervention for autism spectrum disorder are more reliable versus specialized education or interventions (Horlin et al., 2014). A meta-analysis study was conducted on 33 studies that aimed at comparing the success of non-specialists mediated interventions against specialist interventions. These studies involved control groups of children with ASD and findings revealed success of such interventions specifically in social relationship with others, motor skills and skills in communicating with others (Naveed et al., 2019).

Comprehensive ASD approach

Literature recommended several components to be incorporated into comprehensive treatment program such as: (1) addressing the core deficits of autism; (2) instructing in well-organized settings like special need school; (3) reducing leaner-to-teacher ratio; (4) planning for generalization and continuity; (5) promoting family engagement; (6) implementing specific approaches to difficult behaviors; and (7) monitoring the progress regularly (National Autism Center, 2015; Reichow et al., 2018). The table below depicted non-specialist and specialist interventions for ASD found so far with details about the focused problem, delivery agent, training provider, name of intervention, number of sessions, duration of session/ min, program duration and effect size and compared with the effect size of specialist mediated interventions.

Table 3: *Description of study characteristics and effectiveness of non-specialist and specialist interventions for ASD*

Non specialist intervention for ASD						Specialist intervention for ASD			
Focused problem	Author year	Deliver agent	Training provider	Name of intervention	Size effect	Focused problem	Author & year	Intervention	Size effect
Self-regulation	Silva, 2015	Parents	Therapists	QST	0.68 (0.24 to 1.12)	Communication deficit	Dawson, 2010	ESDM	0.45(-0.14 to 1.04)
Symptom severity	Divan, 2018	Parents	Researchers	PASS Plus	0.31 (-0.36 to 0.99)	Cognitive development and behavior	Kasari, 2008	Joint attention	0.38 (-0.24 to 1.11)
	Kuravackel, 2017	Parents	Health workers	COMPASS for hope	0.99 (0.21 to 1.77)		Kasari, 2008	Symbolic play	0.64(-0.06 to 1.37)
	Grahame, 2015	Parents	Professionals	MRBO	0.75 (0.03 to 1.47)		Kim, 2008	Improvisational music therapy	0.40 (0 to 0.78)
	Silva, 2015	Parents	Therapists	QST	0.51 (0.07 to 0.94)		Rickards, 2007	Home based intervention	0.06 (-0.45 to 0.71)
Joint attention	Divan, 2018	Parents	Researchers	PASS Plus	0.32 (-0.44 to 1.09)				
	Kasari, 2015	Parents	Trained interventionists	JASPER	0.16(-0.26 to 0.58)				
	Poslawasky, 2015	Parents	Researchers	VIPP-AUTI	-0.35 (-0.81 to 0.12)				
	Rahman, 2016	Parents	Health workers	PACT	-0.64(-1.16 to -1.11)				
Joint engagement	Divan, 2018	Parents	Researchers	PASS Plus	1.40 (0.42 to 2.39)				
	Ibanez, 2018	Parents	Not mentioned	Enhancing Interactions Tutorial	0.53 (0.14 to 0.92)				

Table 3*: Description of study characteristics and effectiveness of non-specialist interventions for ASD (continued)*

Non specialist intervention for ASD						Specialist intervention for ASD			
Focused problem	Author year	Deliver agent	Training provider	Name of intervention	Size effect	Focused problem	Author & year	Intervention	Size effect
	Kasari, 2015	Parents	Trained interventionists	JASPER	1.42 (0.94 to 1.89)				
	Ko, 2018	Peers	Therapists	START	0.03 (-0.64 to 0.69)				
	Shire, 2016	Parents	Trained clinician	JASPER	0.98 (0.53 to 1.43)				
Social skills	Brian, 2018	Parents	Researchers	Social ABCs	0.07 (-0.57 to 0.43)				
	Corbett, 2017	Peers	Researchers	SENSE	0.98 (0.22 to 1.74)				
	Divan, 2018	Parents	Researchers	PASS Plus	0.48 (-0.21 to 1.16)				
	Ibanez, 2018	Parents	Not mentioned	Enhancing Interaction Tutorial	0.73 (0.03 to 1.13)				
	Ingersol, 2016	Parents	Therapists	ImPACT online	0.68 (-0.09 to 1.46)				
	Matthews, 2018	Peers	Certified peer providers	Peers curriculum	0.56 (-0.10 to 1.23)				
	Morgan, 2018	Teachers	Certified coach	SCERTS	0.34 (0.06 to 0.63)				
	Parsons, 2018	Parents	Researchers	BOBY	0.662 (0.077 to 1.29)				
	Rahman, 2016	Parents	Health workers	PASS	-0.04 (-0.55 to 0.47)				
	Vernon, 2018	Parents	Therapist	START	0.85 (0.16 to 1.54)				

Note. Social Emotional Neuro Science Endocrinology (SENSE) theater; family mediated Preschool Autism Communication Trial (PACT); Parent mediated intervention for Autism Spectrum Disorders in South Asia (PASS); Qigong Sensory Treatment (QST); Joint Attention, Symbolic Play, Engagement, and Regulation programme (JASPER; Social Tools And Rules for Teens socialization (START); Emotional Regulation, and Transactional Support (SCERTS); Therapeutic Outcome By You (TOBY); Applied Behavioral Analysis (ABA); Social applied behavioral analysis (ABCs); PASS plus (pragmatic language, behavioral and sensory stimulation); Early Start Denver Model (ESDM).

1.2. History of psychiatric care in Rwanda

The description of Rwanda's psychiatric history is primarily characterized by four significant historical occurrences, including the pre-colonial, colonial, post-colonial, and contemporary periods (contemporary)(Rwandan Ministry of Health, 2011). The only method for resolving health-related issues among the Rwandan populace during the pre-colonial period was a system entirely run by traditional healers. Together with traditional healers, the family guided by traditional medicine, used to work together to find out solutions of the suffering individual. However, during the colonial time, colonialists ignored the traditional medicine and provided modern medicine, which were successful alternatives to traditional medicine. In 1962, the Brothers of Charity (a Catholic congregation) donated to and worked with the Rwandan government to establish the Neuropsychiatric Hospital Ndera, which marked the beginning of the asylum era that had begun in the early 20th century. The hospital provided psychiatric care in Rwanda. This is just one Neuropsychiatric hospital, however, the hospital was put in place without government legislation or rules governing and regulating psychiatric care in Rwanda (Rwandan Ministry of Health, 2011). The psychiatric care initiated in Rwanda by 1972 operated and existed until the Genocide against Tutsis in 1994 which saw the migration of essential skilled labor force and demolition of infrastructures including hospitals. After the genocide, Rwanda was faced with a number of nationalities affected by psychological trauma. This was exacerbated by the limited and absence of decentralized psychiatric services to address these mental health related problems (Rwandan Ministry of Health, 2011; Heim & Schaal, 2014). The current era, which began in 1995, has been active and distinguished by significant government engagement and commitment through the Rwandan Ministry of Health. Notably, psychiatric care was decentralized to Primary Health Care (PHC), which supports conventional medicine. Combining modern treatment with traditional medicine, Rwanda's public health benefited greatly. (Rwandan Ministry of Health, 2011).

Currently, psychiatric services are delivered by means of decentralized framework consistent with the WHO that recommends integration of psychiatric care into PHC (Zemishlany, 2016). Such decentralization, involves health centers, district hospitals and provincial hospitals. In Rwanda, the health centers, operate under supervision of district hospital. The community health workers serve the local population and their activities are coordinated by the health centers. The integration of community health workers in psychiatric care implemented in Rwanda is consistent with the approach proposed by Funk, Saraceno, Drew and Faydi (2008) and (Lazarus Ray & Freeman, 2009). This approach recognizes the importance of the inclusion of community health workers in identification of people suffering from mental illnesses and conducting informal counselling as well as psycho-education.

The Rwandan Ministry of Health permanently guides and regulates district hospitals responsible for delivering psychiatric services that are accessible and acceptable to local population. District hospitals also offer acute care in psychiatric illnesses. District hospitals refer complicated psychiatric disorders to the national psychiatric referral hospitals for advanced care (Rwandan Ministry of Health, 2016).

Ndera Neuropsychiatric Hospital and CHUK are the only two specialists referral hospital in Rwanda that receive all psychiatric clients from district hospitals (Rwandan Ministry of Health, 2011; Ng & Harerimana, 2016). Rwanda is faced by a shortage of mental health professionals in health care system such as psychiatrists, psychologists and psychiatric nurses. The health centre refers the cases that need district hospital care, appropriate resources, advanced skills of specialists and relevant equipment and infrastructure. The personnel at District Hospital are responsible for delivering advanced therapeutic services including provision of medication, counselling individuals or groups (Lazarus Ray & Freeman, 2009;Todesco, Ostuzzi, Barbui, 2022). Current literature suggests successful decentralization of psychiatric services to PHC facilities, characterized by active engagement of knowledgeable and skilled clinicians working at the PHC settings (Lazarus & Freeman, 2009). However, challenges still remain, even when psychiatric services are integrated in the community health facilities (Rwandan Ministry of Health, 2011).

In conclusion, the history of psychiatric services in Rwanda does not focus on one specific mental disorder. ASD is also included among mental disorders which are managed in all public health facilities in Rwanda, from health centers to referral hospitals. Thus, services for ASD do not have a particular history in the general history of psychiatric care in Rwanda. To the researcher’s knowledge, there is no study on interventions for caring for children with ASD in Rwanda. Once ASD is diagnosed, the child clinicians only manage the symptoms by medication and send the child back home to be cared for by the family. However, there are private initiatives which are involved in the assistance of children diagnosed with ASD. Such initiatives include mainly special need schools that are relatively expensive and unaffordable to low income families. These schools are located in the urban area, Kigali city and include; Autism Rwanda, Initiative for autistic children and adolescents (IACA) Rwanda, Rwanda children Christian school, Heroes Centre for children with disability and HVP Gatagara and Sylver Bell.

1.3. Decentralization of psychiatric services in PHC facilities

Mental disorders including ASD and neurological illnesses globally affect approximately 450 million people (Lazarus & Freeman, 2009). Thus, WHO recommends the reduction of mental illness burden, accessibility of mental health services and advocacy (Zemishlany, 2016). Gauld and colleagues (2012) emphasizes the need of “primary health care of mental health”, to be integrated into PHC facilities which consist of health centres and district hospitals in Rwandan context. These health centres and hospitals deliver inpatient and outpatient non specialists health care for ASD (Zemishlany, 2016). In the same vein, as described in the history of psychiatric care of Rwanda, services for ASD are included in general psychiatric services. There are no speciality services for ASD including the referral pathway of the health system.

Challenges in Decentralization of psychiatric services in PHC facilities

Absence of political support, inappropriate care, overwhelmed facilities, or misunderstandings between health policy-makers and health professionals, have been highlighted in literature as barriers to the integration and decentralization of psychiatric care (Petersen et. al., 2016). Moreover, scarcity of resources were emphasized to be major factors hindering the decentralization of psychiatric services (Dube & Uys, 2016; Jenkins, Baingana, Ahmad, McDaid, Atun, 2011; Lazarus & Freeman, 2009; Petersen et al., 2019; Thornicroft & Semrau, 2019). These authors reasoned that the budget allocated to psychiatric services was insufficient for implementing, decentralization and integration services in PHC facilities, especially in developing countries. For instance, in Uganda, Ssebunnya and research team (2010) reported a very small percentage proportion (one percent) of the budget allocated for mental health services. Inequalities in the distribution of budget allocated in health sector, hindered mental health services regarding essential resources (financial, human and equipment resources). Also, Kigozi and Ssebunnya (2009) and Ssebunnya and colleagues (2010) discovered that there were shortages of specialists in psychiatry, which became the key barrier for integration of psychiatric care in PHC. Moreover, knowledgeable and skilled professionals were needed for effectively managing individuals suffering from mental illnesses. The shortage of clinicians in mental health is considered as a barrier for the decentralization and integration of mental health services (Funk et al., 2008; Petersen et al., 2019).

The challenges are worse in the presence of ASD clinical condition. The challenges faced by children with ASD, like any other disability, include associated costs, long distances to health facilities and limitations of service providers and health care systems. However, there is minimum evidence on the physical and social barriers, inaccessible health care and educational services, faced by children with disabilities (Kidd & Kabare, 2019; Ministry of Local Government, 2021). Due to stigma and concern over social isolation, families of children with ASD (or CwDs) choose to keep them indoors, mainly in rural areas. (Kidd & Kabare, 2019; Ministry of Local Government, 2021). Therefore, families may fail to register their children with the respective authorities, like health centres, leading to underreporting of CwDs (Kidd & Kabare, 2019; Ministry of Local Government, 2021). This compromises the availability and expansion of services through the decentralized mental health services of PHC. Moreover, there is shortage of mental health professionals compounded by the lack of specialists in ASD care as well as lack of appropriate infrastructure and resources needed in the effective management of children with ASD (Petersen et al., 2019).

Benefits of decentralization of psychiatric services in PHC facilities

Although the barriers to the integration were presented, benefits and advantages of integration in PHC were discussed in different studies conducted and reported, decentralization has a number of benefits (Funk et al., 2008; Kigozi & Ssebunnya, 2009; Mwape, Mweemba & Kasonde, 2012; Petersen et al., 2019; Thornicroft & Semrau, 2019). Firstly, the treatment of comorbidities (somatic and mental conditions) are efficiently and effectively managed (Zemishlany, 2016). Secondly, ASD and psychiatric services are availed to the community. This enables affordable, cost effective services and increased human resources capability, thus successfully achieving health outcomes (Chen & Cardinal, 2021; Funk et al., 2008; Patel, Belkin, Chockalingam, Cooper, Saxena & Unützer, 2013).

Thirdly, affordability and accessibility of mental health services allow clinician to detect mental illness early, intervene and follow up clients, therefore reducing risks for complications and chronicity of mental illnesses, in line with principles of prevention of mental illnesses (Compton & Shim, 2020; Funk et al., 2008; Patel et al., 2013). Fourthly, stigma towards mental illnesses decreases when accessibility of mental health services to the population is promoted. This makes it easier for mental health education coverage and increases mental health awareness. Thus stigma among the general population towards mentally ill people and their families is reduced (Javed et al., 2021; Rowan, Grove, Solfelt & Magnante, 2021). Literature indicates that increased levels of contact with mentally ill people reduces the stigmatizing attitude that people hold towards people with mental illness (Baziga, Uwingabiye & Gasovya, 2020; Shahwan et al., 2022; Zhang, Henderson, Magnusdottir, Chen, Ma, Thornicroft, 2022). In summary, the strategic plan aims at preparing and training health professionals in PHC, so that they are equipped with adequate information on mental health, as well as competencies and advanced skills for effectively managing mentally ill people (Petersen et al., 2019; Zemishlany, 2016). Although there are enormous challenges in ASD services, children with ASD will particularly benefit from the decentralization of mental health services. Decentralization increases the accessibility of health care provided at community health settings, bringing them closer to these children, who are kept at home due to the family shame of being stigmatized or excluded from other community members.

1.5. Problem statement

Although ASD is a widely, recognized condition in developed nations, awareness of this neurodevelopmental disorder is very low in developing countries (Bakare & Munir , 2011). Very few studies explore challenges and coping strategies for ASD caregivers and clinicians in SSA, and there is dearth of published research in Rwanda in that. Similarly, the existing evidence-based therapies for children with ASD are from developed countries, and there is few research that inform how to modify them for use in programs focused on Africa. Moreover, there is dearth of epidemiological studies focusing on use of Family focused training care model for autism spectrum disorder in Sub-Sahara Africa (FASSA) interventions in SSA countries including Rwanda. Although there is limited epidemiologic data on ASD from Rwanda, the U.S. Centers for Disease Control and Prevention highlighted the high incidence of ASD and the paucity of autistic-specific schools in SSA. (Bakare & Munir, 2011; Sheldrick & Carter, 2018). Therefore, these challenges remain in spite of commitment by the Government of Rwanda for improving and delivering high quality psychiatric care via decentralization of such psychiatric services for patients in PHC settings, particularly children with ASD. ASD is a debilitating condition that is costly when left untreated, with health care system in SSA, lacking human and financial resources to support long-term interventions (Horlin et al., 2014; Mattie & Hamrick, 2022; Rogge & Janssen, 2019). The current treatment of ASD was developed outside African countries (e.g. America, Europe and or Asia), and hence required systematic and innovative adaptations that are suitable for resource constrained countries in SSA. Thus, the current research intended to come up with situational analysis of ASD in Rwanda with its related challenges and coping strategies of mothers and clinicians as well as a systematic and innovative adaptation of FASSA intervention suitable for Rwanda ASD management.

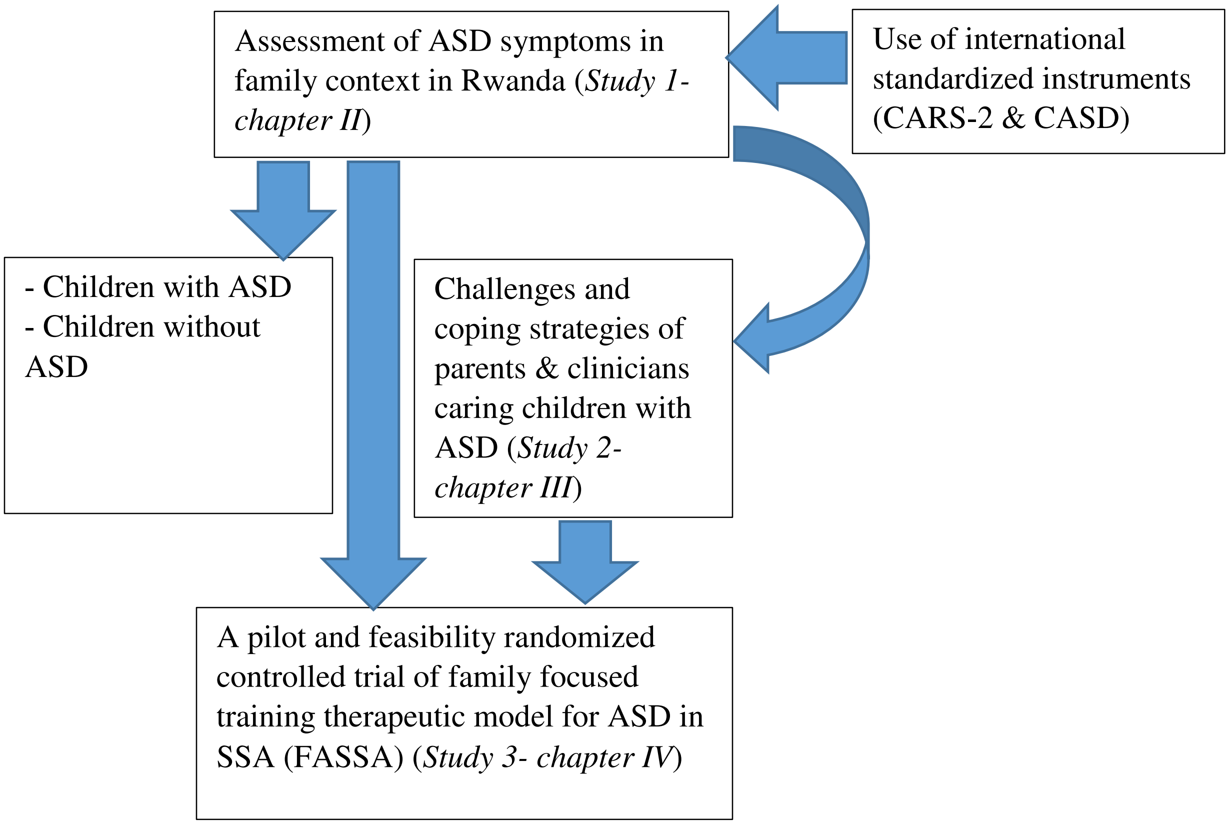
1.6. General overview of the present dissertation, purpose and the general research question

The overall purpose of the present dissertation was to analyze ASD symptoms, challenges and coping strategies of parents and clinician in caring for children with ASD in Rwandan context. Also, it was for adapting the existing evidence-based diagnostic and intervention care to culturally and linguistically suitable tool, for managing children with ASD in Rwanda.

The overarching question was, how to improve assessment and intervention for caring children with ASD in Rwanda. The evidence base for ASD diagnosis and intervention in Rwanda influence ASD therapeutic outcome and allow clarification, in a bid to identify starting points of advancing ASD management.

The present research project dwells on re-assessment of pre-diagnosed children with ASD, identification of challenges and coping strategies of parents and clinicians caring for children with ASD and adaptation and evaluation of treatment/ training manual that contains techniques for the management of children with ASD. Noteworthy, this has been presently missing in the routine care of children with ASD in Rwanda. To achieve this goal, the dissertation addressed firstly, the re-assessment of the pre-diagnosed children with ASD for testing associations between sociodemographic variables and severity of ASD symptoms, reliability and validity and correlation of two international diagnostic instruments (*chapter II*); secondly, the identification of challenges faced and coping strategies of parents and clinicians in caring for children with ASD (*Chapter III*) and lastly, adaptation of treatment manual with the FASSA and a randomized controlled feasibility trial (*Chapter IV*). The results from the first two studies clarified the current status about diagnosis, challenges faced and coping strategies, which in turn informed the adaptation of the ASD intervention. This adaptation will lead to reduction in the core symptoms of ASD. In addition, theoretical background and findings from previous studies on relevant factors as well as Children with ASD needs, skills were taken into account, when adapting the existing evidence based intervention (Manohar et al., 2019). As mentioned on page 6, a flow chart below displays interconnection of empirical studies related to the present dissertation.

Figure 1: The flow chart of overview of the empirical studies for the present dissertation



1.7. Rationale of the present study

The high and rising incidence of people diagnosed with ASD in combination with the life-long care and support, plenty resources (e.g. special education, healthcare and community services), makes ASD a major concern in the society. On top of the emotional and social problems, ASD is coupled with substantial costs for affected individuals and families (Liao & Li 2020). Currently, a number of studies have confirmed that rigorous early intervention in ASD improves clinical outcome, alleviates burdens of individuals and their caregivers (Penner et al.

2015). In addition, the majority of children with ASD fail to access mental health services, thus, stay isolated at home without treatment. Meanwhile, Rwanda has routines for common disorders such as depression or anxiety, however, ASD expertise is lacking. These children with their life-long disorder do not have any chance to get adequate help. Most children with ASD remain undiagnosed and are often kept hidden at home in a state of *de facto* ostracism. They are "treated" by healers and do not access treatment through the health care system. Regrettably, delay of medical consultation and delayed intervention negatively affects not only the growth and abilities of Children with ASD, but also distresses their families, especially parents who have to devote time and energy to cope with dual responsibilities of managing ASD child and provide financial security for their families.

To overcome these challenges, Rwanda started integrating mental health services into general health care facilities from community level to referral levels, with the aim of bringing diagnostic and treatment expertise in ASD care (see 1.3).

Solutions to this complex challenges associated with ASD in children in Rwanda are to (i) raise awareness of ASD, (ii) improve access to and quality of diagnostics and intervention services, and (iii) integrate them into primary health care (PHC) services that are closer to the communities and families faced with ASD (Petersen et al., 2019). While early interventions and behavioral training addressing needs of children and ASD were developed and successfully tested in high-income countries, such programs are not directly applicable to Rwanda and other resource-constrained African countries, as they require both, sufficient financial means to support long-term interventions and highly trained staff. There is shortage of the latter, i.e. psychiatrists and specialized personnel, shifts responsibility and work load to nurses and specialized teachers, who need to be trained and given guidelines and adequate tools. In Rwanda, protocols for detecting, diagnosis and managing ASD do not exist; thus creation of national, provincial and district population-based archives and integrating them to communities is of need. In addition, protocols should be urgently developed to improve the ASD detection and diagnosis among children from different groups of Rwandans. Furthermore, application of school based screening protocols would help to detect children who are under-diagnosed due to low severity of ASD symptoms and cultural variances. To implement new diagnostic and treatment procedures within the health system of Rwanda was of urgent need, addressed by this research project.

Re-assessment of pre-diagnosed children with ASD and a qualitative study interviewing clinicians and parents to children with ASD and clinician caring for them provided the first evidence base that the family focused intervention could be helpful in educating children with ASD and their families (Ntalindwa et al., 2019) . The present research project considered the challenges and knowledge gaps related to ASD in Rwanda and will provide best practice for other countries in Sub- Sahara Africa

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CHAPTER II: ASSESSMENT OF ASD SYMPTOMS IN FAMILY CONTEXT IN RWANDA

2.1. Introduction and background

ASD is a complex long lasting neurodevelopmental illness with early onset (APA, 2013; Nguyen et al., 2021; WHO, 1997). Autism related impairments were discussed and explained in 3 important domains that include communication, social relationships, constricted and persistent unusual behaviors as well as obsessions with amusements, rather than the 2 currently used in DSM-5 of social communication skills and constricted persistent behaviors and obsessions with amusements (APA, 2013; Randall et al., 2018).

The ASD diagnosis and international standardized instruments

ASD is a behaviorally diagnosed condition that requires early detection and diagnosis in a bid to institute timely interventions. Prompt interventions are shown to improve later language, cognitive abilities, and the main ASD symptoms. (van ’t Hof et al., 2021). The worldwide mean age of ASD according to current literature is 60 weeks ranging from 30 to 234 weeks (van ’t Hof et al., 2021). ASD can also be diagnosed in adult psychiatric out-patients who had never before received an ASD diagnosis and even in high-functioning populations at a later stage of development, according to other studies (Hirota et al., 2018). The focus of current researchers or clinicians is early detection and diagnosis of ASD, and timely interventions. This has led to global extensive development and validation of international standardized instruments to screen and diagnose ASD (APA, 2013; Chan, Smith, Hong, Greenberg & Mailick, 2017; de Bildt et al., 2015; Hirota et al., 2018; Lord, Luyster, Gotham, & Guthrie, 2014; Mayes, 2012; Moulton, Bradbury & Barton, 2019). Nevertheless, a significant number of children with ASD miss the chance for prompt ASD detection and early interventions. Also, literature proposes that screening clients for possible referral to specialists should be accomplished, so as to make a diagnosis and provide adequate and early management of ASD among preschoolers and school-age children (Hirota et al., 2018). Furthermore, the body of knowledge also recommends the use of a reference called the gold standard assessment for diagnosis, and involve the intensive clinical judgment of multiple professionals and multiple assessment mechanisms (Randall et al., 2018).

Generally, the ASD assessment is conducted on different domains, which are; cognitive domain, psychomotor domain– behavior and adaptation skills, communication-verbal and gestures. It is performed by experienced multi-disciplinary team through use of observation, clinical judgment and information provided by parents or caregivers to Children with ASD (Randall et al., 2018). This assessment should help clinicians in making a decision of ASD after exclusion of other possible psychiatric conditions (Randall et al., 2018).

As mentioned above, several international standardized instruments were validated for ASD diagnosis. The ADI-R, ADOS-2 and CARS were put forward as the gold standard of ASD diagnosis, and one tool alone must be avoided in diagnosing ASD (Levante, Petrocchi & Lecciso, 2019; Moulton et al., 2019). Therefore, many studies have been conducted, aimed at investigating the correlation between two or more diagnostic instruments for ASD and its reliability and internal validity (Moulton et al., 2019). For example, correlation was tested and findings showed a positive correlation between ADI-R, ADOS-2, CARS, CASD and SRS (Moulton et al., 2019). Again, correlation and good concurrent validity (agreement of 93%) was noted between CARS and CASD, indicating that these tools would provide the same information on ASD diagnosis (Mayes, 2012). Such excellent correlation between CARS and CASD, their good sensitivity and specificity and their brevity and simplicity led the decision on choice of the researcher for using these instruments for diagnosing and assessing eligibility of children with ASD. Thus children with ASD participated in the intervention for management of ASD. In several countries, although a number of instruments were developed, validated and tested to investigate correlation and congruence between them, tested ASD instruments in the Rwandan context were absent according, to the researcher’s knowledge. Current literature lacked documentation on the use of international standardized instrument for ASD diagnosis in Rwanda (see 1.3). Therefore, the present study tested and examined the reliability, concurrent validity and correlation between the two international standardized instruments (CARS-2 and CASD) for ASD diagnosis to address the current gap in literature.

ASD symptoms and sociodemographic factors

Literature reveals that severity of symptoms of ASD correlate with sociodemographic variables. Such as gender, age (both children and parents), level of education, parent unemployment or employment, level of family income (social class) (Skylark & Baron-Cohen, 2017; Taylor et al., 2021). For example, a study conducted by revealed increases in severity of ASD symptoms in middle childhood than early childhood and decrease in girls than boys. This study, also showed that a decrease in severity of ASD symptoms was associated with high education level for parents and older parental age whereas increase of ASD symptoms was associated with low level of education among parent, younger parental age and low income (Skylark & Baron-Cohen, 2017; Waizbard-Bartov, Einat et al., 2022)

Other studies conducted in Vietnam and Denmark stressed contribution of environmental factors in ASD; such as birth in urban area, gender, and mother occupation (Hoang, Vui, Quynh, Ngoc, Duc, Van, Harry & Ha, 2019;. Vassos, Esben, Ole & Carsten, 2016). According to Hoang and colleagues and Vassos and colleagues, children with ASD living in urban areas are exposed to have higher severity of ASD symptoms than children who live in rural the environment. Hypothesizing that some socio-demographic variables are associated with the severity of ASD symptoms, requires studies with large samples, comparison ASD diagnostic criteria as well as case-finding methods in different cultural contexts (Zeidan et al., 2022). On the other hand, the influence of socio-demographics has been reported extensively in several international studies conducted in areas where autism is prevalent (Cogley et al., 2021; Fulton, Paynter &Trembath, 2017; Nguyen et al., 2021)

Although the relationship between sociodemographic factors (for children: age, gender, living conditions, birth conditions; for parents: age, level of education, family social class mother employment) and ASD symptoms' severity have been investigated by other researchers in different countries, the influence of school enrollment for children with ASD, occupation and socioeconomic status of parents of children with ASD, were not explored. Again, this relationship was not investigated in the Rwandan context and clarification of whether sociodemographic factors were specifically for fathers or mothers was not researched.

In this study, for the Rwandan context, the relationship between unexamined sociodemographic factors (for children: age, gender, community of living, condition of birth and admission at school and for mothers: age, occupation, level of education, ubudehe category of families and mother employment) and severity of ASD symptoms were explored. Also, as mothers of children with ASD are more impacted and anxious than fathers are, they were given special attention. (McCafferty & McCutcheon, 2020; Rankin, Paisley, Tomeny & Eldred, 2019). For the present study, the research questions are displayed in the table below.

Table 4 : *Research questions for the study 1 (Assessment of ASD symptoms in family context in Rwanda)*

Research aims	Research questions
Aim 1	1. Do male children present with severe ASD symptoms than female children?
	2. Do school aged children present with severe ASD symptoms than preschool aged children?
	3. Do children living in rural community present with severe ASD symptoms than children living in urban community?
	4. Do children enrolled in schools present with severe ASD symptoms than children not enrolled in schools?
	5. Do children born under abnormal conditions present with severe ASD symptoms than children born under normal conditions ?
	6. Do the 1st born children present with severe ASD symptoms than 2nd born children

Table 4: *Research questions for the study 1 (continued)*

Research aims	Research questions
Aim 1 (continued)	1. Are there differences in ASD severity of symptoms for children of mothers between the ages 19-33 years, 34-48 years and 48-64 years?
	2. Are there differences in ASD severity of symptoms for children of mothers who uneducated, primary educated, secondary educated and university educated?
	3.Are there differences in ASD severity of symptoms for children of mothers who are unemployed, public servants, self-employed and private servants?
	4. Are there differences in ASD severity of symptoms for children of mothers with one child and those with more?
	5. Are there differences in ASD severity of symptoms for children mothers who are in socio economic status class 1, 2, 3 and 4?
Aim 2	6. Do CARS-2 and CASD reliably assess ASD symptoms in Rwanda?
Aim 3	7. Does CARS-2 total score correlate with the CASD total score in Rwanda?
Research hypothesis	There is positive correlation between CARS-2 mean scores and the CASD mean scores in evaluation of ASD

2.2. The study aims

Aim of the present study is threefold.

1. To analyze difference between the means of groups in sociodemographic characteristics (children with ASD and mothers' sociodemographic characteristics), achieved on CARS-2 and CASD in Rwanda.

2. To find out reliability and validity of CARS-2 and CASD in the assessment of ASD symptoms in Rwanda.

3. To identify the correlation between two international standardized instruments (CARS2 and CASD) used to diagnose ASD among Children with ASD in Rwanda.

2.3. Research hypothesis for the study one

The choice of hypothesis for the study one, was based on current literature in terms of the severity of ASD symptoms and agreement between international standardized instruments for measuring ASD (Hoang et al., 2019; Skylark & Baron-Cohen, 2017; Taylor et al., 2021; Waizbard-Bartov, Einat, 2022). In addition to research questions, the hypothesis was formulated for the study 1: there is positive correlation between CARS-2 mean scores and the CASD mean scores in evaluation of ASD.

2.4. Materials and Methods

The research materials and methods section deliberates on how the present research was deliberated (Burns & Grove, 2009). The methods were discussed as follows; research setting, research population, Sampling, recruitment and design, Structure and protocol of the study, tools for data collection, calculation and statistical analysis, data management and ethical issues involved in the present study.

2.4.1. Research setting

The research settings included 2 referral hospitals in Kigali city, CHUK and Ndera Psychiatric Hospital, community homes of 3 Kigali districts, which are Nyarugenge, Gasabo and Kicukiro districts, and 5 Provincial districts, closer and less than an hour's travel to Kigali city, Kamonyi, Muhanga, Gakenke, Gicumbi and Rwamagana districts. In addition, special needs schools, Autisme Rwanda in Gasabo district and HVP GATAGARA de Gikondo in Kicukiro districts respectively, were considered as research settings.

The health facilities (referral and district hospitals) and special needs schools facilitated the researcher to contact and meet parents of Children with ASD. CHUK and Ndera Psychiatric Hospital are national referral hospitals for District hospitals where psychiatric patients including children with ASD are referred to, for advanced psychiatric care. Health centres refer patients to district hospitals. Health centers, are the starting points for persons suffering from mental illness, where essential and basic mental health care is delivered. These comprise counseling or provision of essential medications in line with the essential medication list specified in the WHO (2019).

When there is need for advanced care, the client is transferred to the district hospital which in turn transfer clients to Ndera Psychiatric Hospital or CHUK mental health Unit (Rwandan Ministry of Health, 2020). Health centers provide mental health care services to their communities including the special needs schools, under the supervision of District hospitals. In the communities, community health workers contribute towards psychiatric services and they are supervised by their respective health centers (Niyigena et al., 2022).

2.4.2. Research population

Research population comprised children of 4-12 years of age, receiving treatment services at public/ government, at different levels, either health center, district or specialized levels. The diagnosis of ASD in Rwandan health facilities is made by clinicians (psychiatrists, psychiatric nurses and clinical psychologists) working in health facilities. In view of that autism spectrum disorder frequently has comorbidity, that is, Children with ASD have minor or major psychiatric comorbidity, the study included the Children with ASD with minor psychiatric comorbidity which did not take priority on treatment, in a bid to achieve a statistically significant sample.

Inclusion criteria;

- Pre-diagnosed children with ASD, who were receiving treatment services at public/ government or private facilities, at different levels, either health center, district or specialized levels
- Children with ASD with a complete contact address of their respective families and communities/ villages where there were living.
- Four to twelve years old.
- Parents who accepted to consent for participation in the present study

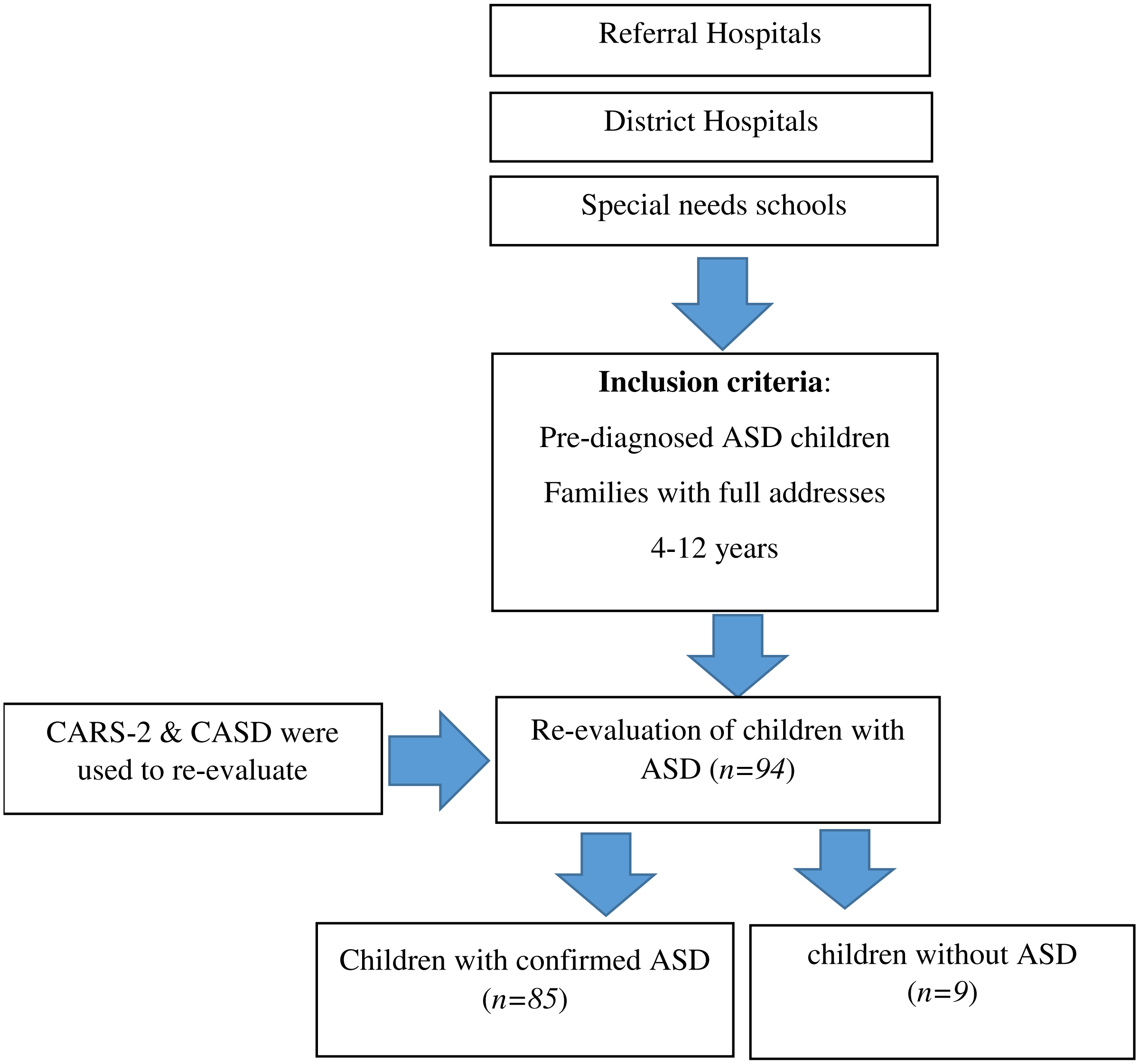
Exclusion criteria;

- Presence of major, severe and chronic psychiatric/ neurological disorders that took priority on treatments, as psychosis/ schizophrenia, major depression and bipolar disorders.
- Children with ASD with known visual and hearing impairments
- Non-Kinyarwanda speaking.
- Refusal to consent for study participation

2.4.3. Sampling, recruitment and design

In the present study, the convenient and purposive sampling methods were employed for the recruitment. A sample of 94 children with ASD was recruited (*M*=7.79; *SD* = 2.57 *Min.*= 4 and *Max.*= 12). The starting points were the government district, provincial and referral hospitals, special needs schools in Rwanda, that were providing ASD services to children. There, the complete contacts for Children with ASD families were acquired. The contact address consisted of telephone parent's number and physical address of the ASD child where they lived or could be located, that is, the Province, district, sector, cell and village.

Figure 2: The flow-chart of participant recruitment for the study 1



The researcher then created a network link with community health workers, psychiatric nurses, psychologists or head of the health center at district hospitals. Appointments in the respective community/ village of the ASD child, was made telephonically. Researcher then, located the homes of Children with ASD, signed informed consent was obtained from parents. Eligible families scheduled diagnostic confirmation process at home. The diagnostic process was done by the researcher himself and included clinical features collection through parents' description of symptoms and the researcher observation

2.4.4. Structure, protocol of the study

Before the data collection, study permits were granted by University of Rwanda-College of Medicine and Health Sciences Institutional Review Board (CMHSIRB), Rwandan National Ethical Committee (RNEC), the Rwandan Ministry and National council of Science and Technology (NCST). Additionally, the researcher obtained informed consents from parents and clinicians. This assessment aimed at, firstly, re-evaluation in a bid to confirm the diagnosis of Children with ASD who had attended or received services from public and private facilities in either levels of care, and secondly, those who met the DSMV ASD criteria.

Each child was evaluated at one-time point of assessment only. The diagnostic confirmation was conducted through the ASD clinical assessment clinical tools which are described and explained under the part of the procedures. These clinical tools included CARS-2 (Moulton, Bradbury & Barton, 2019) and CASD (Mayes, 2012). The study was clarified and informed consent from parents was obtained, before the assessment began. Explanations consisted of description of ASD symptoms.

2.4.5. Tools for data collection

2.4.5.1. Assessment methods (battery)

This study was conducted using a quantitative design. Therefore, the assessment methods included structured interview, behavioral observations in addition to parents'/ caregivers reports.

2.4.5.2. General measures

Socio-demographic form

A demographic form was used through a structured interview, to assess demographic and environmental factors data. In this study, demographic information comprised age, gender, community of living birth order history of birth complications like hypoxia and intracranial hemorrhage and school attendance.

The classification of age was based on Age Phenome Knowledge Base (APK) that was recently developed and suggested for medical researches (Geifman, cohen & Rubin, 2013). Here, nine (9) age groups were defined and suggested with the following ranges: 0–2, 3–5, 6–13, 14–18, 19–33, 34–48, 49– 64, 65–78, and 79–98 years (Geifman et al., 2013). In the present study, the inclusion criteria in terms of age was 4-12 years. Thus two categories were considered to be used for collecting information about children age. These categories include preschool age (4-6 years) and school age (7-12 years). Also, the gender, community of living, school, delivery and birth condition were categorized into two categories, as well. The current study reported specific socio-demographic and environmental factors which are associated with ASD and which influenced mental health services delivered to Children with ASD and their improvement. Socio-demographics influences have been reported extensively in several international studies conducted on ASD (Fulton et al., 2017; Memari et al., 2013). Parental data consisted of their age, level of education, occupation, and ubudehe category. Ubudehe categories were established for the first time in 2000 by the Government of Rwanda, as a strategy to reduce poverty in Rwandan population as they could guide decision makers for national plan. This categorization was based on family income and include ubudehe category 1 (very low income), category 2 (low income), category 3 (moderate income), and category 4 (high income) (Rwanda Ministry of Local Governance, 2021).

Childhood Autism Rating Scale version 2 (CARS-2)

CARS-2 appears in several studies for diagnostic confirmation and categorization of the Children with ASD. This tool was developed by Eric Schopler and his colleagues in America (Ozonoff et al., 2005). The same research team (Schopler and colleagues) developed an ASD diagnostic categorization system by CARS-2 (Chlebowski, Green, Barton & Feinet, 2013;

Moulton et al.2019). The current literature is not indicative of this tool use in sub-Saharan Africa countries. CARS-2 consists of 15 items that are measured in the range of 1 to 4, with a maximum score of 60 and the minimum score of 15. A total score ranging from 15 to 29.5 is considered as no autism condition, 30 to 37 mild ASD, 37 to 45 moderate autism and 46 to 60 scores are considered as severe autism. In this study CARS-2 was not used alone, but was combined with CASD ((Mayes, 2012). Details of items on CARS-2 are found on appendix 3.1.

Validity and reliability

CARS-2 has been exercised extensively in international studies for autism screening or diagnosis (Dawkins et al., 2016; Yaylaci & Miral, 2017). The CARS is a reliable scale with an exceptional internal consistency with Cronbach alpha coefficient of .87 (Breibord and Croudace, 2013). For the current research Cronbach's alpha coefficient of CARS-2, was $\alpha = .84$. Furthermore, CARS has a good sensitivity values ranging between 71% and 85% and specificity ranging between 75% and 79% (Moon et al., 2019).

Checklist for autism spectrum disorder (CASD)

The CASD was developed and validated by Mayes and colleagues in 1999. It has a list of 30 items aimed at evaluating symptoms of autism (Mayes, 2018; Mayes et al., 2009). To evaluate the symptoms, interviews were conducted on parents, the children's teachers and children themselves as well as using available file records (Mayes et al., 2009). The CASD allowed therapist to identify whether a child exhibited symptoms of Autism or not. Details on CASD items are shown on appendix 3.2.

Validity and reliability

The CASD has also been extensively applied in other studies and proved highly valid and reliable (Mayes, & Calhoun, 2011; Mayes, Calhoun, Mayes, & Molitoris, 2012; Mayes et al., 2011; Mayes & Calhoun, 2009). These authors demonstrated that CASD differentiated clearly autism and ADHD from normal children with sensitivity of 100% and specificity of 86.4% (Mayes & Calhoun, 2009). The CASD is both a screening and diagnostic tool also successful in identifying High Functioning Autism (HFA) and Low Functioning Autism (LFA) (Mayes & Calhoun, 2011). The CASD corresponds with the DSM-IV in making clinical diagnosis of autism (Mayes, Calhoun, Mayes, & Molitoris, 2012). The CASD is a scale that has high diagnostic agreement, that is, internal validity, with other assessment tools for ASD that include the CARS-2 (Mayes & Calhoun, 2009), the Gilliam Asperger's Disorder Scale (Mayes & Calhoun, 2009), DSM IV (Mayes et al., 2012) and the ADI-R (Mayes, 2018).

For reliability purposes, a Cronbach alpha coefficient must be above .70 for a scale (Pallant, 2013). CASD recently displayed excellent internal consistency, of Cronbach alpha coefficient .97 (Mayes et al., 2012). Relevantly, the Cronbach alpha coefficient for this study was .95, above .70.

2.4.5.3. Translation procedure

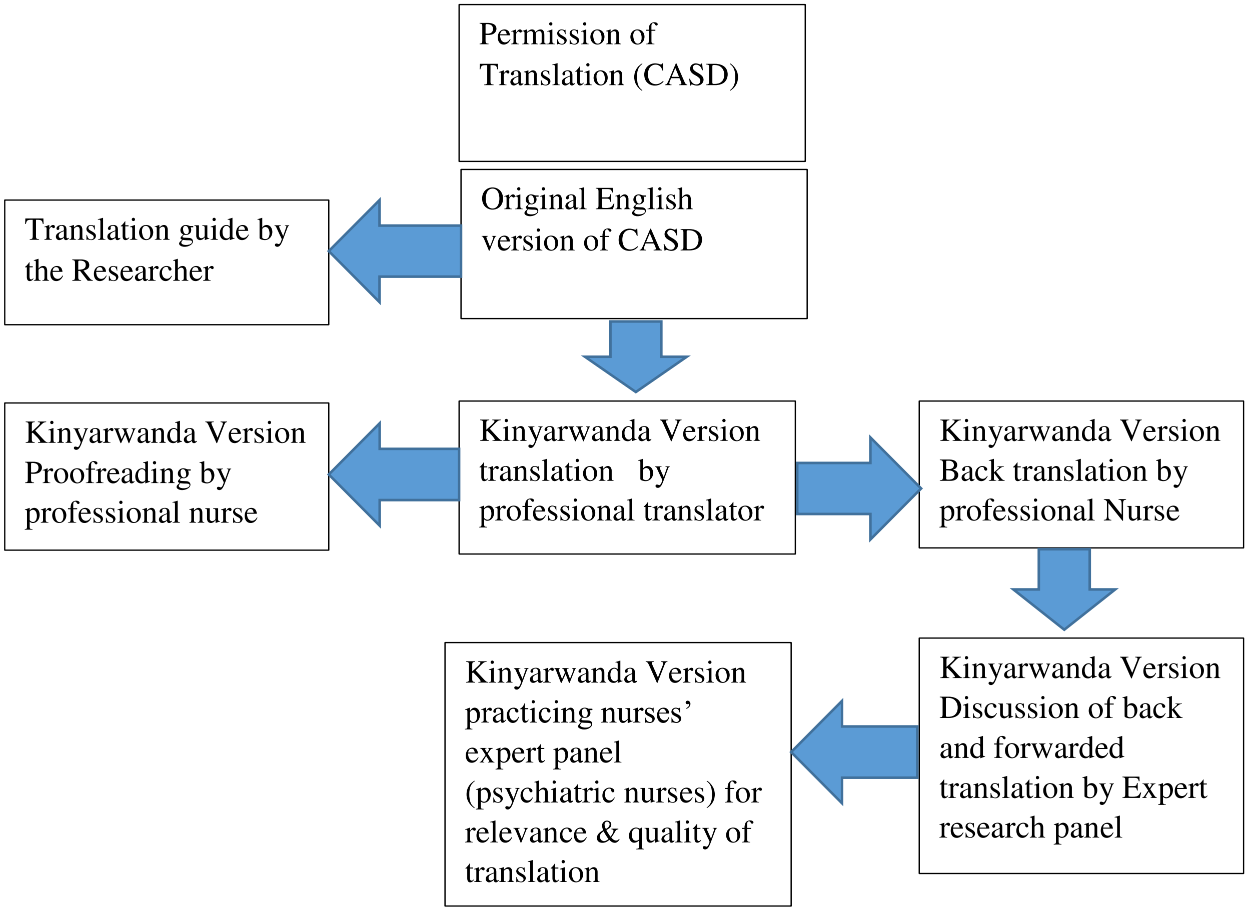
The original CARS, CASD were presented in English and their translation into Kinyarwanda was required because some parents in Rwanda are unable to use English version. The local language of all Rwandans is Kinyarwanda. The official languages recommended by Rwandan constitution are English, French and Kinyarwanda (Republic of Rwanda, 2015). However, the teaching medium of instruction was conducted in French before 1994 and English appeared only in 2008 when there was a reform from French to English (Lewis, Sarah; Freedman, 2010). Moreover, locally, a number of Rwandans have not attained the tertiary level education, where English is used. Thus, translation to Kinyarwanda was recommended then implemented through the forward translation and backward translation.

Contributions from expert research panel in rating the relevance of questions and the quality of translation by the practicing nurses' like the psychiatric nurses and psychologists is vital (Lee, Chinna, Lim & Zainal., 2019). The translation was performed prior to participants' recruitment for the study and it was done on all data collection instruments after receiving the authors permission (Gorecki et al., 2014). The researcher relied on the considerable skills and resources available at the University of Rwanda to ensure linguistic or conceptual equivalence of the instrument translated. The researcher is Rwandan native and bilingual, thus developed a translation guide, then the forward translation from English into Kinyarwanda was executed by a professional and experienced translator (Gorecki et al., 2014).

Secondly, the translation and proofreading process was performed by the Rwandan bilingual professional academic staff whilst the back translation was done by the researcher.

Thirdly, the forward and back translation was approved by researcher expert panel, that is the, native Rwandan and bilingual lecturers, after reviewing, checking and validating (Gorecki et al., 2014; Lee et al., 2019; Younan & Clinton, 2019). Then the final version was administered to practicing nurses' expert panel for rating the relevance of questions and the quality of translation. For the major problematic areas in translation, the researcher consulted the key persons in other countries as South Africa and Germany, and by drawing on the considerable skills and resources available at the University of Rwanda to ensure linguistic or conceptual equivalence of translated instrument.

Figure 3: The translation process of research instruments



The translation was done for CASD after the authors had agreed to their translation to Kinyarwanda, Rwandan local language. For CARS-2, the English version was indicated because the respective authors failed to provide the authorization for proceeding to a translated version as they were unavailable. Authors involvement in the translation process was the requirement for the use of CARS-2 translated version. Test- retest of Kinyarwanda translated CASD tool and English version (CARS-2) was employed, and declared reliable, thus, Cronbach's reliability coefficient was computed. Cronbach's reliability coefficient for CARS-2 was .85 while reliability coefficient for CASD was .86. According to Pallant (2013), a Cronbach α coefficient of a scale should be above .70 (Burns & Grove, 2009; Pallant, 2013). The translation process is presented below.

2.4.5.4. Rating procedure

The therapist who is an experienced psychiatric nurse specialist and a PhD candidate rated all children with ASD as confirmed by clinicians from health care facilities in Rwanda. Due to COVID 19 consequences, the therapist undertook an independent training in Rwanda on CARS-2 and CASD manuals as recommended by its respective authors. The therapist revised these manuals totally before embarking on the diagnostic processes of confirming the ASD diagnosis which had been carried out by mental health professionals in Rwanda.

As mentioned in the section on general measures, the CARS-2 displays 15 items that are rated from 1 to 4 scores for each to get 60 scores in total. CASD is composed of 30 items, which are rated by 0 or 1 for each to acquire 30 scores in total.

The rater (PhD candidate) used at least two hours to observe the autistic child, while a parent was interviewed. This was intended for description of the symptoms presented by the child with ASD as observed by the parents presently and previously. So, the rating was based on the observation during interaction with child by the therapist (playing with the child) and the description of symptoms by parents. Where it was possible, puzzle game, playing the small ball and card game were used to create opportunities of interacting with the child. The choice of the game was guided by the child interest. Due to financial constraints and cultural context, the rating process was not videotaped.

2.4.6. Calculations and statistical analysis

A total sample of *N* = 94 children, 4-12 year-old who were seen or receiving ASD treatment services at public/ government or private facilities, at different levels, either health center, district or specialized levels was recruited. Data collection was carried out using international standardized instruments (CARS-2 and CASD) and socio-demographic form. The socio-demographic form helped to obtain demographic data from Children with ASD and from parents to children with ASD. The children demographic data collected was age, gender, community in which children were living, school enrolment and birth condition, whilst demographic data of parents with Children with ASD consisted of mother's age, education, occupation, and family social class. International standardized instruments measured ASD symptoms for 15 items on CARS-2 and 30 items on the CASD as presented on page 49.

According to the study conducted by Moulton and colleagues (2019) the CARS-2 is categorized into three domains. The three domains are social communication (items 1,2,8,11,12,14, and 15), emotional reactivity (3,6 and 10) and stereotyped behavior sensory sensitivity (4,5,9 and 13). The above mentioned authors decided on the exclusion of the item 7 (visual responses) as its wording was a bit vague, which may lead to variation in score in regards of the item.

Some professionals may measure the item in consideration of eye contact of the child and others in consideration of the child behavior in regards to visual sensory status, for example, unusual visual and sensory seeking. Although two items, the degree and consistency of intellectual response" and "general impressions loaded on social communication domain, did not seem to reflect social or communication abilities of the child and clinicians considered variation in a child's intellectual status to identify symptoms of autism. Consequently, the measure item of intellectual response is the same ways key features of the disorder are assessed. In addition, the clinicians may consider their general impression as impairment of social and communication aspect which are always said to be key features of autism (Moulton et al., 2019).

Socio-demographics in the present study were considered as independent variables whereas the scores achieved on CARS2 and CASD were considered as the dependent variables. Data was captured using statistical analysis package for social Sciences (SPSS), Version 22. Socio-demographic data was changed into numerical values or categorical data. No data went missing within different sections that were part of the instruments completed.

Individual scores per participant was obtained at the completion of CARS-2. For example, items scored for a total score of 60, and 3 scores per sub-scale, resulted in individual scores per participant. Regarding CASD, 30 items scores were 30, and 6 scores for sub-scales, which were; problems with social interaction, perseveration, somatosensory disturbance, atypical communication and development, mood disturbance and problems with attention and safety.

Participants' socio-demographic factors and clinical statistics were summarized using descriptive statistics. Significant associations between socio-demographic factors and dependent variables, that are, the scores achieved on CARS-2 and CASD were calculated using independent- samples t-tests and analysis of variance (ANOVA).

The parametric tests were chosen due to the following assumptions; (1) sample size was more than 30, (2) continuous scale was used and dependent variable was measured at the interval level; (3) the present study is a real life research that violates the assumption of scores that should be obtained using random sampling; (4) independence in observations as observations or measurements were not influenced by any other observation or situation; and (5) homogeneity of variance as in the present study, samples were obtained from populations of equal variance (Pallant, 2013).

In this study, sociodemographic factors variables were considered as independent variables while ASD symptoms, as scores on CARS-2 and CASD, were considered as dependent variables. Pearson's r was used to investigate correlation between CARS2 and CASD. Statistical significant was considered when a p-value was less than *.05* (Pallant, 2013).

2.4.7. Data management

The clinical data was pseudonymized for research purposes only and was not shared with third parties. A link sheet that connects identification number to subjects name was kept under lock and key in the researcher's office at University of Rwanda and will be destroyed 10 years later as suggested by Eberhard Karls Universität Tübingen and University of Rwanda research policies. Likewise, the hard copy records are stored in researcher office at the University of Rwanda and destroyed as soon as the study was completed. All the data was entered into MS

Excel spreadsheet for management and analysis. Data will be kept for 10 years and can be removed upon participants' request. Dissemination data was influenced by participants in the study.

2.4.8. Ethical considerations

Research Permits

University of Rwanda (CMHS/IRB) granted ethical clearance (Ref.: No334/CMHSIRB/2020) and initial protocol, amendments were made. The said amendments involved reducing the number of participants owing to ASD related stigma demonstrated in the study on challenges and coping strategies for parents and clinicians caring for children with ASD, as approved by University of Rwanda (CMHS/IRB) (Ref: No151/CMHSIRB/2021). Again, amendments were made in shifting from effectiveness study to feasibility and pilot study, changed the existing evidence based intervention for autism to be adapted as well as changed the data collection instruments to be used. The approval to conduct research was granted by the National Health Research Committee (NHRC/2019/PROT/071) (Appendix 1.1) and Rwanda National Ethics Committee (RNEC) (Ref.: 165/NCST. 201(Appendix 1.2). Permission for conducting research was obtained from participants' respective institutions and Districts and informed written signed consents had to be obtained from parents who participated in this study.

Autonomy and respect

Informed consent forms were offered to parents with Children with ASD and participants were provided with all the information that was necessary and sufficient for the study. In order to take a voluntary decision of taking part in the present research, confidentiality, potential risks and benefits were considered. This information about the study enabled participants in making informed choices of participating in this study. A signed informed written consent (Appendix 5.1) was requested from each research participant, including parents of Children with ASD and clinicians managing Children with ASD. Participant's names were not used in the study for confidentiality purposes. The informed consent form included contact address of the Chairman of CMHSIRB which could be used by participants in the case of concerns on their part about the study.

Risks

The therapy was conducted by the researcher who is a psychiatric nurse specialist and the expert advisory board (EAB) offered support and advice to implement the protocols successfully. There were no significant and non- medical risks associated with the study since the ethical principles were strictly adhered to. It was unexpected that recruitment or interview questionnaires administration could be unduly stressful, nor that the participants could experience discomfort and loss of privacy during interviews or interventions. In the case of stress or discomfort, the researcher would initiate breaks or termination upon realizing emotional instability on the part of participants. The procedures put in place for minimizing discomforts in participants, included, careful selection, training and systematic preparation of the participants. The researcher demonstrated ability to work with participants as far as the target population was concerned, and was able to answer the questions that could arise and deal with discomforts that could have occurred during the interview or intervention. In addition, the counseling team comprising a mental health nurse and a clinical psychologist working from the respective district hospital were prepared to intervene in the case where psychological problems arose during the interview and intervention stages.

Data encryption/ secrecy

Confidentiality norms were reviewed and the safeguards to protect confidentiality on research instruments and other data were strictly enforced. Patients were presented on study data sheets by means of study numbers. Besides, the data was coded to conceal participants' identification and no patient' names nor hospital ID numbers appeared on the study forms. Study codes and names were stored separately in the researcher's office at University of Rwanda. Both patients' study ID numbers, names and hospital/health center numbers were kept by the researcher as hard copies in a secure location.

2.5. Results

2.5.1. Research participants' characteristics

Findings from the present study revealed that most of children pre-diagnosed with ASD were confirmed with severe ASD (50%; $n = 47$). In addition, these findings showed that the majority of pre-diagnosed children with ASD was ASD confirmed (90.4%; $n = 85$); while the minority (9.6%; n = 9) was unconfirmed. Table 5 displays the distribution of participants' characteristics (children with ASD).

Table 5: *Descriptive statistics of the sample (Children with ASD)*

Variables	Number	%
Category of ASD		
Absence of ASD	9	9.6
Simple ASD	11	11.7
Moderate ASD	27	28.7
Severe ASD	47	50
Age (years)		
Preschool aged	31	33.0
School aged	63	67.0
Mean ± S.D	7.79 ± 2.57	
Gender		
Female	19	20.2
Male	75	79.8

These results suggested that unconfirmed children with ASD was below the cut off on both diagnostic instruments (CARS-2 and CASD) used for the evaluation purposes (30 scores and above for CARS-2 and 16 scores and above for CASD).

Regarding the age of pre-diagnosed children with ASD, age groups were divided into two classes, pre-school age and school age. As indicated in table above the school age constituted most participants 67% (*n* = 63) whist the minority were Children with ASD with preschool age (33%; *n* = 31). Male participants formed 79.8% of the research participants (*n* = 75), whereas female research participants representing only 1 ⁄ 5 (20.2%, *n* = 5).

Table 5: *Descriptive statistics of sample (Children with ASD - continued)*

Variables	Number	%
Community of living		
Rural	22	23.4
City	72	76.6
School enrolment		
enrolled	33	35.1
No enrollment	61	64.9
Birth condition		
Normal	80	85.1
Abnormal	14	14.9
Birth order of child		
1st born	40	42.6
2nd born and more	54	57.4

About the community living, most participants (76.6%; *n* = 72) lived in city areas whist the minority lived in the rural areas (23.4%; *n* = 22) and this explains why the study was conducted mainly in Kigali city.

Most children with ASD, according to the current study (64.9%; *n* = 61) were not enrolled in school, i.e. the nursery and primary schools when their chronological age allowed them to be enrolled in schools. Slightly, more than a third of Children with ASD (35.1%; *n* = 33) were enrolled in schools i.e. the classic schools or basic special needs schools. Perhaps, this lack of enrolment to schools was due to both the shortage of special needs schools and ASD stigma related issues. Owing to ASD stigma, children may not be accepted or admitted in classic schools because of their unwanted behaviors.

Finally, the majority of pre-diagnosed children with ASD were born through normal vertex delivery with (94.7%; $n = 89$) and under normal conditions (85.1%; $n = 80$) whist the minority of participants were born under other modes delivery (5.3%; $n = 5$) and in the presence of birth complications (14.9%; $n = 14$). Also, the result from the present study showed that the majority of children with ASD was the second born in family (57,4%; $n = 54$); while those whose were first born in family were less represented in the study sample (42.6%; $n = 40$).

Table 6: *Descriptive statistics of the sample (mothers to children with ASD)*

Variables	Number	%
Community of living		
Rural	22	23.4
City	72	76.6
School enrolment		
enrolled	33	35.1
No enrollment	61	64.9
Birth condition		
Normal	80	85.1
Abnormal	14	14.9
Birth order of child		
1st born	40	42.6
2nd born and more	54	57.4

The table 6, displays that the majority of mothers of Children with ASD (77.7%; $n = 73$) were between the ages 19-33 years at child's birth whilst the minority (22.3%; $n = 21$) was in the middle age class (33-48 years old). There were no mothers aged 49 and above. The present study showed higher knowledge levels among participants with university education. There were two

(2.1%, *n* = 2) mothers only, who were uneducated and the majority of mothers were educated up to high school (25.5%; *n* = 24) and university level (31.9%; *n* = 30). It is not surprising then because most participants' mothers were Kigali city inhabitants where there is more access to educational opportunities than in rural areas.

Table 6: *Descriptive statistics of the sample (mothers to children with ASD (continued))*

Variables	Number	%
Occupation		
None	5	5.3
Public servant	19	20.2
Agriculture	16	17.0
Self-employment	44	46.8
Private servant	10	10.6
Number of children in family		
1 child	8	8.5
2 children and more	86	91.5
Socioeconomic status (Ubudehe categories)		
Category 1	5	6.4
Category 2	22	23.4
Category 3	66	70.2
Category 4	0	0

Pertaining to mothers' occupation, (46.8%; *n* = 44) were self-employed and 5.3% (*n* = 5) were jobless. The self-employed occur mostly in the study population possibly owing to mothers abandoning their jobs to devote more time in taking care of children. Families that have one child suffering from ASD were less represented in the sample (8.5%; *n* = 8) while the majority of families have more than 2 children (91.5%; *n* = 86).

The socioeconomic status (Ubudehe categories) for participating families, ranges from a minimum category 1 and a maximum of category 3. The category 3 was the most represented with 70.2% (*n* = 66) whilst the category 4 was not represented in this study (0%; *n* = 0).

2.5.2. Difference between means scores of groups of socio-demographic characteristics achieved CARS-2 and CASD.

As stated in the introduction of this section, independent – samples t-test and the ANOVA, tested difference between means (Pallant, 2013). The sociodemographic characteristics for Children with ASD as age, gender, community, school enrolment and birth condition as well as the sociodemographic characteristics for mothers with Children with ASD as mother's age, education, occupation, and social classes were the independent variables while scores achieved on the CARS-2 and CASD were dependent variables (Pallant, 2013). Present study, reported significant associations only.

Children with ASD sociodemographic characteristics

To compare the scores achieved on CARS-2 and CASD total scores versus socio-demographic factors of children with ASD, independent–samples t-test was calculated. This research displayed no statistically significant difference in scores (achieved on CARS-2 and CASD) for groups of the following children sociodemographic characteristics: Age, gender, school enrollment, community in which ASD children live and birth order. However, it revealed statistical significant difference between means of two birth conditions of children with ASD, achieved on CARS-2. This results suggest that children born under poor conditions (*M*=45.80, *SD* = 8.31561) displayed more ASD symptoms than children who were born under good conditions (*M* = 40.42, *SD* = 11.94677; *t* (92) = 2.08, *p = 0.40*, two-tailed). The extent of differences in the mean (mean differences = 5.37, 95% *CI*: .23 to 10.50) was insignificant, Cohen; (small effect) = (40.42-45.80)/10.292587= 0.5). There are useful websites that provide an easy and faster manner of calculating an effect size statistics that include Cohen's d (Pallant, 2013). For example, in the present study the Cohen calculator was used (https://www.socscistatistics.com/effectsize/default3.aspxwas used, was used to calculate

Cohen's *d)*. These results indicated that children with ASD who were born in poor conditions are more affected than children with ASD who were born in good condition.

Table 7: *Difference between means scores of groups of socio-demographic characteristics achieved CARS-2 and CASD: Children with ASD*

	CARS-2				*CASD*			
	M	*SD*	*T*	*p*	*M*	*SD*	*t*	*p*
Age children								
Preschool age	46.77	8.04	1.335	.185	23.06	3.63	1.533	.129
School age	44.13	9.48			21.56	4.84		
Gender								
Female	46.11	9.21	.592	.555	22.89	3.98	.908	.366
Male	44.72	9.08			21.84	4.64		
School enrolment								
Enrolled	44.67	8.99	-.261	.795	22.03	4.59	-.36	.971
Not enrolled	45.18	9.18			22.70	4.51		
Community								
Rural community	46.27	7.17	.750	.455	22.50	3.90	.528	.599
Urban community	44.61	9.59			21.92	4.70		
Condition of birth								
Poor condition	45.80	8.31	2.078	.040	22.41	4.01	1.867	.065
Good condition	40.43	11.94			20.00	6.55		
Birth order								
1st born	43.78	10.16	-.979	.330	21.75	5.19	-.585	.585
2nd and above born	45.91	8.16			22.28	3.97		

Note: *t*= t-value, *p*- p-value, *M*=mean, *SD* = Standard Deviation and Significant at the $p<0.05$ level

Sociodemographic characteristics: Mother of children with ASD

The ANOVA was used to analyze the difference between means of groups in sociodemographic characteristics of mothers (age, education, occupation and the socioeconomic status), achieved on CARS-2 and CASD. As displayed on table 10, the ANOVA (age, education, occupation and the class) and independent–samples t-test (number of children) showed no statistically significant difference between means of groups in sociodemographic characteristics, achieved on the CARS-2 and the CASD. Also, independent–samples t-test was calculated to test difference between means of groups (the number of children in family), achieved on CARS-2 and CASD. However, significant difference was showed between means scores of mothers age groups at child birth, achieved on CARS-2 and CASD. Participants were divided into two groups according to their age (group 1: 19-33 yrs and group 2: 34-48 yrs). For mother age at child birth and CARS-2, there was a statistically significant difference at the $p < .05$ level for the three age groups: F 1:92) = 7.16, $p = .009$. However, the actual difference in mean score between groups is too small. Effect size was calculated using the following formula; Effect size = Sum of squares between groups/ Total sum of squares (Pallant, 2013). In the present study effect size was .07 suggesting small effect. Post hoc comparison using the Tukey HSD indicated that the mean score for group 1 ($M = 43.69$, $SD = 3.88$) were significantly different from Group 2 (M = 49.52, $SD = 4.75$). These results suggest that children with ASD from older mothers are more affected than children from younger mothers. Regarding CASD, also there was a statistically significant difference at the $p < .05$ level for the three age groups: F 1:92) = 5.24, $p = .024$. The actual difference in mean score between groups is large and the effect size was .05 suggesting small effect. Post hoc comparison using the Tukey HSD indicated that the mean score for group 1 ($M = 21.49$, $SD = 3.88$) were significantly different from Group 2 (M = 24.00, $SD = 4.75$). Much like CARS-2, these results suggest that children with ASD from older mothers are more affected than children from younger mothers.

Table 8: *Difference between means scores of groups of socio-demographic characteristics achieved CARS-2 and CASD: Mothers of children with ASD*

	CARS-2					*CASD*				
	M	*SD*	*df*	*F*	*p*	*M*	*SD*	*df*	*F*	*p*
Mother age at child birth										
19-33	43.70	9.37	1	7.162	.009	21.49	4.75	1	5.249	.024
34-48	49.52	6.25				24.00	2.89			
Mothers education										
Not educated	51.00	9.89	4	.695	.598	26.00	4.24	4	.835	.506
Primary education	43.59	10.34				21.41	5.00			
Secondary education	44.68	9.28				27.76	4.69			
University education	46.60	6.99				22.83	3.63			
Mother occupation										
Public servant	44.74	7.34	4	.631	.642	21.98	3.67	4	.311	.870
Agriculture	44.75	10.49				21.44	5.63			
Self-employment	45.57	9.28				22.43	4.78			
None	48.80	9.88				23.00	4.63			
Private servant	41.50	6.81				21.10	3.03			
Number of children										
1 child	45.50	9.28	92	.219	.872	22.80	5.05	92	1.023	.598
2 and more children	44.95	9.11				21.98	4.49			
Socioeconomic status (Ubudehe category)										
Category 1	44.83	10.75	2	.265	.265	21.83	4.66	2	1.400	.252
Category 2	42.27	10.20				20.68	5.14			
Category 3	45.92	8.48				22.53	4.25			

Note: *df*= degree of freedom; *F*= variation between samples, *p*= p-value, *M*= Mean, *SD*= standard deviation and Significant at the p<0.05 level

2.5.3. Reliability and concurrent validity

Findings from the present study indicated that both CARS-2 and CASD are reliable and valid in the diagnosis of ASD. Of the 94 pre- diagnosed children with ASD, 85 were diagnosed with typical ASD, while 9 were not autistic. The confirmed children with ASD comprised of

HFA (11.7%, n=11) and LFA (78.7%, n=74). For reliability, the present study revealed that CASD displayed a Cronbach's alpha of .78 indicating excellent internal consistency for 30 CASD symptoms/ items, while CARS-2 displayed a Cronbach's alpha of .84, demonstrating excellent internal consistency for 15 CARS-2 symptoms/ items. Regarding concurrent validity, this study revealed an agreement between the CASD and CARS-2. Moreover, the present study compared the CASD and CARS-2 and the diagnostic conformity between the two instruments was 100%. The children with confirmed ASD scored in the ASD range on both CASD (16-30) and CARS-2 (30-60), while 9 with unconfirmed ASD scored below the cutoff, on both CASD (> 30) and CARS-2 (> 30).

2.5.3. Correlation between CARS2 and CASD total scores

A Pearson correlation test was computed to assess a linear correlation between total score (ASD symptoms) achieved on CARS-2 and CASD. Findings from the present study showed that total scores achieved on CARS-2 were in correlation with total score achieved on CASD. Findings of significant correlations (small, medium and large) are reported. To investigate the strength of the correlation, Cohen's guidelines is considered; weak (r=.10 to .29), moderate (r=.30 to .49) and strong (r=.50 to 1.0) Pallant (2013)

These correlations are detailed and displayed in Table 13. Firstly, findings of the present study revealed significant large positive correlation between total score achieved on CARS-2 and total score achieved on CASD (r= 1.00, n=94, p<0.001) suggesting that an increase on CARS-2 total score results in increase of CASD total score. To sum up, this association between total scores on CARS-2 and CASD correspond with this research expectation (hypothesis) as well as other previous studies stating that CARS-2 is congruent with CASD in ASD evaluation. Thus both CARS-2 and CASD can be used in Rwandan context and have consistent results in evaluation of ASD.

2.6. Discussion

The present discussion of findings was undertaken based on the study one objectives and questions. Research aims for study 1 were to: (1) analyze difference between the means of groups in socio-demographic characteristics, achieved on CARS-2 and CASD; (2) find out reliability and validity of CARS-2 and CASD in the assessment of ASD symptoms in Rwanda and (3) test correlation between CARS-2 and CASD used in Rwandan sample of children suffering from ASD.

Since ASD is a complex neurodevelopmental disorder that affect considerably routines of Children with ASD particularly and generally their families, current literature suggests that early ASD identification and intervention could ameliorate the outcomes of autistic children, evidenced by a reduction of ASD symptoms (Manohar et al Manohar, Kandasamy, Chandrasekaran & Rajkumar, 2019). Recently researchers saw rising interests in the identification of risk factors associated with ASD. Thus, the present study was done since very little was known about the socio-demographic factors of autistic children and their mothers in Rwanda.

2.6.1. Difference between means scores of groups of socio-demographic characteristics achieved CARS-2 and CASD.

2.6.1.1. Socio-demographic characteristics of children

Age of children with ASD

The present research revealed no significant differences between means of school age and preschool age groups of children with ASD, achieved on CARS-2 and CASD. Results are well aligned with Hidalgo and colleagues' research in Spain (Europe) who noticed no differences between preschool aged autistic children and school aged children ($p=0.18$). The same findings were found in Pakistan (Asia) by Aslam and research team, that there was no difference between means scores of preschool aged autistic children and school aged children groups (p=0.34).

Gender of children with ASD

In line with previous studies, the present study revealed no significant gender differences in means scores between female children with ASD and male children with ASD, found across measures of ASD symptoms (Fulton et al., 2017; Hidalgo, Moreso & Sans, 2021; Irum, Muhamad, Iram & Naveed, 2022). However, a study conducted by Cogley showed a significant risk factor of male children in ASD symptoms (Cogley et al., 2021). The significant differences between male and female was also reported by Hwang, Davidovich and Bakian in studies conducted in 2013, 2018 and 2019 respectively (Davidovitch et al., 2020; Hwang et al., 2013; Kuzniewicz, Wi, Qian, Walsh, Armstrong & Croen, 2014). Also, findings from the present study contrast findings revealed in research done in Vietnam by Nguyen and research team and Hoang and colleagues suggesting that mean scores of males were more than mean scores of females as was indicated on scores achieved on CARS (Hoang et al., 2019; Nguyen et al., 2021).

Community of living

The current study, revealed no significant differences in scores between children living in rural areas and children with ASD living in urban areas, in contrast to findings of Hildargo in Spain (Hidalgo et al., 2021) who reported that urban population has less ASD diagnoses than rural population (59% vs 81%; p=0.001). However, in a study conducted in Vietnam and Denmark, findings revealed that children born in urban areas are more exposed to develop ASD than children who born in rural areas (Hoang et al., 2019; Vassos et al., 2016). Other studies are necessary to explorer the risk of ASD symptoms among urban children as compared to rural children. This could be related to the fact that psychiatric care in most cases is inaccessible and unavailable to the rural population (Newman, Hawrilenko, Jakupcak, Chen, Fortney, 2022). Thus urban population is more knowledgeable about mental disorder including ASD, promoting consultation, diagnosis and attainment of clinical interventions. Rurality is associated with negative attitudes towards treatment seeking, perceived need of treatment leading to lessor initiation and engagement in mental health interventions (Newman et al., 2022).

School enrollment

Association tests revealed no significant differences in scores between children enrolled in school and those who are not enrolled (special need schools or mainstream schools). This could be because these schools are currently offering minimal services to Children with ASD. To the researcher's best knowledge there were no previous studies comparing Children with ASD enrolled in schools with those who are not enrolled. To the best of our knowledge, this study is the first to investigate the difference between means scores of children with ASD enrolled in school and those who are not. The present study brings a novel information in the current literature about the relationship school enrollment and ASD symptoms.

Birth condition and birth order

On the other hand, the present study revealed significant differences in means total scores achieved on *CARS-2* between children with ASD born in normal conditions and those born in abnormal conditions. These findings are similar with results found in several studies exploring antenatal, perinatal and post-natal factors and ASD, and determined significant associations between ASD and birth conditions (Davidovitch et al., 2020; Kuzniewicz et al., 2014; Robert et al., 2017). However, these findings contrast the previous study conducted by Cogley reporting no significant differences between children groups regarding the birth conditions (Cogley et al., 2021). In line with the *birth order of children with ASD*, the present study revealed an insignificant difference between means scores of children groups based on the birth order, achieved on CARS-2 and CASD. However, this is inconsistent with other findings. For example, a study conducted in Malaysia reported that the earlier order of birth in the family was significantly associated with ASD (OR=0.68; 95% CI, 0.59; 0.77) and concluded that earlier birth order is an independent risk factor for developing autism among Malaysian children (Ann et al., 2020). The same findings were reported in Australia and Turkey that confirmed the association between increasing birth order and variability in ASD clinical phenotypes at diagnosis. Moreover, the study conducted in Australia revealed that the first born without siblings exhibited reduced cognitive functioning than those who are first born with siblings but this study did not show differences between children groups regarding the siblings number (Alvares et al., 2020; Ugur et al., 2018). The order of birth is the sequence of birth amongst siblings. Other literature insinuate that the first born child, during labor is exposed to more birth passage stress than their siblings leading to congenital complications like respiratory distress, asphyxia (Biederman, 2005; Cheng et al., 2019). These complications during delivery may lead to minimal brain damage which in turn lead to the development of ASD (Biederman, 2005; Cheng et al., 2019)

2.6.2.2. ***Socio-demographic characteristics of children***

Taking into account the difference between the means of groups according to mothers socio-demographic characteristics (education, occupation, siblings number and the socioeconomic status) achieved on CARS-2 and CASD, the ANOVA test revealed no statistical significant difference between the means of groups in sociodemographic characteristics. These findings contrast the study by Hidalgo, Moreso and Sans (2021) who observed a significant difference in scores achieved on CARS-2 and CASD between high standards families with good socio economic background and those with poor socio economic status ($p=.001$)(Hidalgo et al., 2021). Also, these researchers showed a significant difference in scores of autistic children from families whose mothers were working in industry economic sector and those who were working in agriculture economic sector ($p=.001$). However, the present study revealed a significant difference between the means scores of three groups of mothers of children with ASD according to their age at birth (group 1: 19-33 years and group 2: 34-48 years). These results suggest that children with ASD from younger mothers are less affected by severity of ASD symptoms. These findings are similar to international studies implying that the increasing age of the mother contributes to the development of ASD. For example, in Malaysia a study substantiated that the older age is significantly associated with the ASD symptoms (OR=1.04; 95% CI, 1.001; 1.07)(Ann et al., 2020).

Regarding *maternal educational status*, findings from the present study contrast the study conducted previously in Pakistan that brought to light a significant difference in ASD symptoms between autistic children to literate mothers and those to illiterate mothers ($p=0.0267$)(Irum et al.,2022). Irum and colleagues, stated that lower level of educational status of parents especially mothers who are always near to children, can be the cause of inappropriate care of children with ASD (Irum et al., 2022).

2.6.3. Reliability, concurrent validity and correlation between 2 measures for ASD (CARS-2 and CASD)

The present study found excellent internal consistency between items on both CARS-2 and CASD in the assessment of ASD symptoms among children. Also, findings revealed full agreement between CARS-2 and CASD in assessment of ASD symptoms performed in Rwandan context. Moreover, the present study showed a positive correlation between CARS-2 and CASD that suggests that an increase in CARS-2 score correlates with increased scores achieved on CASD. In other words, these international standardized tools can be used to acquire the same results in terms of ASD symptoms. Results from studies conducted in USA pointed out a strong positive correlation and agreement between CARS-2 and CASD; positive correlation between CASD and GADS (.82 and .81, respectively) and significant correlations $p<.0001$ (Mayes et al., 2012). Murray and colleagues emphasizes that with other autism instruments, CASD had high diagnostic agreement; such as CARS (98%) for LFA (Murray, Dickerson & Smith, 2011).

Findings from the present study and other studies affirm that brief rating scales for ASD (CASD and CARS) are completed in fifteen minutes by clinicians or parents with strong psychometric support. A study conducted by Mayes in 2009 revealed a good diagnostic accuracy in classifying children with ASD versus ADHD (1-16 years) as measured by CASD used by parents (89.6%). However, the accuracy is very good when the CASD is used by clinicians (99.6%) than parents (Mayes et al., 2009). The above mentioned authors, support the idea of allowing parents to use CASD independently, but contend that some parents may slightly underrate autistic symptoms. Thus, to obtain best validity, the brief measures (CASD and CARS-2) are to be completed by clinicians (Mayes et al., 2009).

Generally, identification of children with ASD is crucial and should be done as quickly as possible to help ASD to access evidence based interventions, that is, the early intensive behavioral intervention. The early intensive behavioral intervention is proved successful when initiated in early childhood. The early identification and intervention for ASD can be done using instruments. Concerning the instruments to be used for early ASD identification, literature recommends those that do not require expertise and extensive training, and that which are brief, inexpensive, simple to administer and score (Mayes, 2012; Mayes & Calhoun, 2009). Examples of the brief instruments include CARS-2 and CASD which can allow the therapist to evaluate many autistic children as much as possible in very short space of time; thus reducing the cues or waiting lists in different clinical settings. The brief measures are commended than the lengthy assessment instruments as health insurances pay a pre-fixed rate for the process of diagnostic assessment nevertheless of whether the evaluation last 1 or 2 hours or 15 or 30 minutes. These brief measures are compulsory in Sub Sahara Africa, including Rwanda, where, there is a shortage of mental health specialists at primary and secondary health care levels (Rwandan Ministry of Health, 2011; Yusuf, Linu, Emmanuel, Evelyn, Mitchelle & Lilian, 2021). Due to lack of mental health specialists in the community levels of care, children suspected with ASD need to be referred from community level to specialized health facilities for confirmation of the diagnosis and advanced mental health care (Rwandan Miniatry of Health, 2020; Rwandan Ministry of Health, 2011). Some international instruments for ASD take more than 2 hours to be completed, and these are, ADI-R and ADOS. Thus, these hinder its feasibility for rapid assessment and diagnosis of ASD in different setting like schools, busy clinical settings and large populations (Constantino & Gruber, 2005; Ward-King et al., 2010). Again, researchers may be discouraged to use ADI-R and ADOS for conducting studies since it is time consuming and expensive, which may hinder subjects' participation in research. This may lead to small research samples size with limited power of generalizability (Murray et al., 2011).

2.7. Conclusion

The current study aimed at investigating the use of two international standardized instruments to diagnose ASD and to determine the relationship between sociodemographic variables and the severity of ASD symptoms. Findings from this study revealed no, statistical, significance between socio-demographic factors both for autistic children (age, gender, living area, school attendance) and mothers to children with ASD (education, number of siblings, occupation and social class) and ASD symptoms as measured via CARS-2 and CASD. However, the current study discovered that there is an association between the birth condition, mother's age at birth and the severity of ASD. Thus, birth condition and the age factors are considered amongst several socio-environmental factors associated with ASD development. This aids in understanding which socio-environmental factors trigger the complexity and variability of ASD characteristic features. Furthermore, the current study showed a strong positive correlation between CARS-2 and CASD indicating that both instruments can help to gather the same information concerning the ASD symptoms. Thus, both CARS - 2 and CASD are promising tools to capture the relevant information on the symptoms of ASD.

2.8. Limitations

The present study had several limitations; *firstly*, the sample was not representative for Rwandan context as it involved children with ASD only in Kigali and 5 districts close to Kigali. Thus, it cannot be generalized in Rwanda, on ASD symptoms and related socio-demographic factors. Therefore, there is need of study with a large sample size, obtained from multiple clinical settings, to add on what is known about the risks factors of ASD in the Rwandan population. Again, the sample was too small to allow identification of intensive correlation between ASD severity and related factors and for computing the validation of the diagnostic instruments in Rwandan context. Thus, the findings are not generalizable to the broader Rwandan population. In addition, there was no intelligence quotient (IQ) data for the children with ASD who have below average intelligence. More studies are required for duplicating the present results and more studies with large samples are needed in Rwandan context for determining the comparative diagnostic accuracy by testing validity and reliability (both inter - later reliability and internal consistency) of CARS and CASD in comparing children who have ASD and those who do not have ASD (normal children), and by clinical comparison group of ADHD since it is common in childhood psychiatry. ASD and ADHD may have similar clinical characteristics as attention deficits, hyperactivity, behavior and mood troubles, initial language delay, and deficits social skills. Furthermore, items and factor analysis of the CASD and CARS is needed and very important to determine whether some items are unnecessary therefore be shortened.

Secondly, the present study may have biases as the study included only parents who consented and the study included only children who were diagnosed with ASD (*N*=94) by health professionals, where no children from the general population who took part in the present study.

Thirdly, the present study did not utilize the gold standards in ASD evaluation (ADOS and ADI-R), which could have quantitatively evaluated the ASD features of the research participants. These instruments may elucidate the relationship between ASD clinical features and socio-demographic factors respectively. Also, there is questionable independence or objectivity as the data collection was done by one person (the researcher/ therapist) only. Thus a data collection done by two or more people is needed for comparison to ensure the objectivity.

CHAPTER III: CHALLENGES AND COPING STRATEGIES OF PARENTS AND CLINICIANS CARING CHILDREN WITH ASD IN RWANDA

3.1. Introduction and background

ASD is as a long-lasting neurodevelopmental disorder confirmed once impairment is noticed in every day functioning. Parents react with shock, distress and confusion upon receiving an ASD diagnosis (Divan, Vajaratkar, Desai, Strik-Lievers & Patel, 2012). Internationally and locally including Rwanda, the confirmation of ASD diagnosis is made by using international standardized diagnostic measurements which include DSM-5. The DSM-V is utilized by multidisciplinary team of health professionals in different clinical settings in Rwanda for ASD diagnostic purpose (Vllasaliu et al., 2016). Literature suggests that receiving ASD diagnosis promotes initial relief and awareness of the child's problems and accessibility to specialized facilities for early intervention (Calzada, Pistrang & Mandy, 2012). However, parents are faced with challenges specific to ASD management due to long life commitment of care, dealing with stressors and lifestyles changes in the family in terms of managing ASD (Reddy, Fewster & Gurayah, 2019).

This is of special concern in Rwanda and sub-Saharan Africa (SSA), where there is a lack of understanding about ASD and modern diagnostic and treatment methods. Both international and local studies highlight financial resource limitations in healthcare, schooling and changes in the family unit following an ASD diagnosis (Cloete & Obaigwa, 2019; Reddy et al., 2019). These changes in families include fulfilling specific needs of the ASD child, changes of parent's attitudes and skills to accommodate the ASD child and families social isolation (Divan et al., 2012). Moreover, ASD pose economic burden to the family owing to additional necessities of life. Both parents are emotionally affected by the ASD condition and become depressed, anxious, frustrated and overwhelmed by the situation since ASD is long-life long condition (Reddy et al., 2019). All of the challenges mentioned above are intensified by lack of knowledge about ASD, particularly, skills to be used for managing the ASD as a new situation hence affecting the existing family functioning.

Unexpectedly, health professionals who are supposed to be skilled and knowledgeable, are also faced by challenges related to ASD management. In Asia, Minhas and colleagues discovered poor awareness of the ASD condition amongst front line care providers, with its resultant effects of ineffective management (Minhas et al., 2015).

Generally, there is dearth of published research on the challenges faced by health professionals as well as for management of Children with ASD in Rwanda, with only a few studies in SSA on that. Moreover, the current literature uncovers the presence of limited health care resources including financial and human resources, which causes frustration among health professionals, about the outcome of ASD condition (Roughan, Parker & Mercer, 2019). This is supported by Ministry of Health in Rwanda acknowledging existence of limited skills and knowledge, tools and protocols as the prominent challenges in the decentralization of psychiatric services (including ASD services) into Rwandan primary health facilities (Rwanda Governance Board [RGB], 2018). Thus, this study aims at exploring challenges faced by clinicians in ASD management and their coping strategies.

Faced with challenges to care for Children with ASD, the parents of Children with ASD and clinicians have adopted coping strategies to deal with these challenges. The coping strategies are to be supplemented by the individuals available resources as well as inner qualities of positive behaviours, thoughts and emotions (Reddy et al., 2019). Reinforcing this, is the local and international literature indicating that parents use several coping strategies to deal with ASD related challenges (Chu, Mohd, McConnell, Tan & Joginder, 2020; Cloete & Obaigwa, 2019; Minhas et al., 2015; Reddy et al., 2019).

Among the coping mechanisms include self-education, acceptance, rest, support groups, and faith in supernatural forces, among others. (HA, 2018). In a research done in Kenya, parents held the view that their children's ASD condition was a result of God's will and that only God knew what their children's future held (Cloete & Obaigwa, 2019; Gona et al., 2019). Thus, parents engaged in intensive prayers, which fostered resilience in them.

The acceptance of the diagnosis had a positive influence on parental adjustment and coping with the situation, hence applauded. In addition, access to respite and social support were important coping strategies since they allowed the family to have time away from Children with

ASD and also permitted parents to spend time with Children with ASD, thus helping them to tolerate disruptive and maladaptive behaviors permanently presented by the Children with ASD (Giovanni, Calhoun, Carter & Anwander, 2020). Recent literature also highlights that parents seek to understand the ASD condition from one's experience, thus this is another strategy used to cope with Children with ASD (McCafferty & McCutcheon, 2020). In view of this, parents recommended the organization of social networks through associations and thus created platforms that would grant them opportunities to share experiences related to ASD condition.

Similarly, literature has revealed that clinicians adopt coping strategies to overcome ASD related challenges. A study conducted by Cloete and Obaigwa (2019) proposed that peers may help in adjustment of challenges faced by a colleague through sharing living and working experiences. In Israel, Sinai-Gavrilov and colleagues (2019) stressed the importance of mutual learning from each other amongst the multidisciplinary team members. For example, colleagues have different opportunities within units of care that promotes care providers to share experiences and resolve the problems they have.

Despite the decentralization of mental health services into Rwandan PHC facilities since 2005, very few studies of local autism related research was noticed, specifically regarding to challenges and coping strategies of parents with Children with ASD and clinicians caring for Children with ASD and who expected to implement such integration (RGB, 2018).

3.2. Study aims

The study aims were to:

1. Identify challenges faced by parents to children and clinicians providing ASD services in Rwanda

2. Describe coping strategies of both parents with Children with ASD and clinicians providing ASD services.

Based on previous research and own experiences, questions linked to the current research are following; (1) What are challenges faced by parents of Children with ASD and clinicians caring for the Children with ASD in Rwanda? (2) What are coping strategies adopted by parents of Children with ASD and clinicians in caring for the Children with ASD in Rwanda?

3.3: Methods and materials

3.3.1. Research setting & participants

The research settings included 2 referral hospitals in Kigali city, CHUK and Ndera Psychiatric Hospital, community homes of 3 Kigali districts, which are Nyarugenge, Gasabo and Kicukiro districts, and 5 Provincial districts, closer and less than an hour's travel to Kigali city, Kamonyi, Muhanga, Gakenke, Gicumbi and Rwamagana districts. In addition, special needs schools, Autisme Rwanda in Gasabo district and HVP GATAGARA de Gikondo in Kicukiro districts respectively, were considered as research settings.

This study opted for purposive sampling method. Twenty (n = 20) parents and twenty (n =20) clinicians were recruited. The sample of parents and clinicians in charge of mental health services were drawn from records (registers and patient files) of health facilities and special need schools providing ASD services, within the community of Children with ASD. The records were availed to researchers who obtained study permits to conduct the study from respective institutions. For parents who participated in the study, age ranges for their autistic children were 5 years to 12 years old, 15 males and 5 females.

Table 9: *Social demographic variables of parents and clinicians*

Participants	Education		Age	Gender		Experience	
	High school/ primary	University	Range of Age	Male	Female	≤5 yrs.	≥5yrs
Parents	11	9	30-53 years	6	14	8	12
Clinicians	3	17	29-51 years	9	11	9	11

As mentioned in the previous study (*study1*) the study permits were granted by research regulatory institutions in Rwanda (CMHS institutional review board and National health research committee and Rwandan Ministry of Health. Also, the National Council of Science and Technology gave its approval for the study's permission to be conducted. All parents and clinicians were offered written informed consent for participation.

3.3.2. Research approach and design

As explained above, the care of Children with ASD is provided by parents and clinicians in Rwanda. To obtain more information about the care rendered by the local ASD services and coping strategies of parents with Children with ASD and clinicians caring the Children with ASD, the present study provided an account of challenges and coping strategies used by parents and clinicians. Therefore, a qualitative and descriptive phenomenological design was adopted to assist the researcher to better understand lived experiences of parents with Children with ASD and clinicians managing the Children with ASD. Additionally, this type of approach allowed the researcher to observe and collect nonverbal information from participants during interviews.

3.3.3. Data collection and materials

An interview guide was developed to help the researcher to conduct an extensive semi-structured, tape- recorded interview on parents and clinicians, for data collection purposes. Each interview lasted between 50 minutes and one to a half hour. The questions on the interview guide were open ended in nature and had been developed based on research questions to be answered (Braun & Clarke, 2006).

The open- ended questions followed by probes and follow up questions for eliciting breadth and depth in participants' responses was used. Along with interviews, the researcher took written field notes about his observations considering the non-verbal expression of the research participants. The field notes were useful in learning and bracketing, and a reflective diary as well as peer discussions, improved the quality of subsequent interviews. All interviews were conducted in the Kinyarwanda language.

3.3.4. Data analysis

The memo notebook (field notes) was consulted several times during the whole process of analysis specifically on coding and quotes selection level. The data analysis was done by the researcher in collaboration with two independent academics, who are experts experienced in qualitative analysis and Kinyarwanda native speaking. Prior to analysis, transcripts were developed by the researcher from audio records and double checked by an independent experienced nurse. The analysis was performed in Kinyarwanda transcripts (Ho, Holloway & Stenhouse, 2019; van Nes, Abma, Jonsson & Deeg, 2010). The translation and back translation of Kinyarwanda version into English started at themes and subthemes level for reporting purposes by independent professional, bilingual and experienced translator (Ho et al., 2019).

An expert panel committee (affiliated to the University of Rwanda) reviewed and approved the translation work (Al-Amer, Ramjan, Glew, Darwish & Salamonson, 2015). Themes and subthemes back translation from English to Kinyarwanda was done for comparing with those from the original language by an expert, bilingual and experienced nurse. In addition, for report writing and publication purposes, the needed quotes to be used were translated and back translated (Kinyarwanda-English-Kinyarwanda) as English is the reporting language for this study. NVivo12 software program (QSR International) was utilized to organize and access data.

For the current study the thematic analysis techniques, were employed for data analysis purposes (Braun & Clarke, 2006). Codes were created, refined from transcribed text, for parents and clinician's interviews and grouped into a final set of themes and subthemes respectively. According to Braun and Clarke, a theme may be developed on the basis of the number of the times it occurs. It may be relatively rare but considering the overall data, it becomes a significant issue (Braun & Clarke, 2006). A theme should reflect research questions which makes the researcher display a degree of flexibility on decision about themes included in the research report (Balubaid & Sahab, 2017; Braun & Clarke, 2006).

3.3.5. Trustworthiness:

Dependability, conformability credibility and transferability, were maintained on recruitment of clinicians with varying levels in clinical experience at different health care facilities for the trustworthiness purposes (Connelly, 2016). Also, the researcher recruited parents with varying status levels in terms of experiences with ASD child, gender, and social economic status. All children except one due to limited financial resources, were enrolled in a special needs school with varying degrees of severity of ASD.

3.4. Findings

Theme 1: Challenges faced by parents of Children with ASD and clinicians in caring Children with ASD

Challenges faced by Children with ASD' parents in caring for Children with ASD

Lack of information: All parents expressed lack of information about ASD condition. It is the leading challenge faced by parents caring for Children with ASD and has negative impacts on the improvement of ASD symptoms, as parents are unaware of how to behave or manage children with ASD condition. The parents only become aware and search for autism related information only when clinicians give them the diagnosis.

> *"I am short of knowledge about autism which turns out to be a big challenge. This underlies difficulties in terms of the behavior to adopt on our part and the way of coping with such a child" (Parent No.11).*

Parents in turn reported limited information about ASD among health professionals, which compelled them to search for any possible solution or available treatment of autism accessible and affordable to them. The easiest alternative to modern treatment is traditional medicine that is availed to Rwandan community inhabitants. Furthermore, parents held religious beliefs regarding the causes of ASD.

> *"In Rwanda there are traditional everywhere in both urban and rural area and this had worked long time ago. Traditional healers have many clients who consult them even if I did not approach them as I believe in power of God", (Parent 02)*

Some parents articulated the presence of traditional healers everywhere in Rwandan communities and others were advised by their own parents to consult traditional healers. However, few parents have consulted traditional healers for support with less success.

Frustrations regarding the child ASD condition: Parents in this study reported stress, depression and hopelessness following ASD confirmation, since ASD is a long life condition. In addition to, health professionals who were expected to manage Children with ASD, lacked the confidence in caring for them. In harmony with these parent's statements, some health professionals did not conceal or hesitate to declare their knowledge deficit pertaining ASD management. Thus, parents were worried about the future and mismanagement owing to lack of knowledge and skills on a number of health professionals managing their children with ASD.

> *"Medical and professional staff are not knowledgeable and skilled enough to take care of autistic children following the absence of specific autism services within health facilities including health centers. The said medical staff and professionals are quite confused which renders me hopeless. Now I wonder whether or not my child will be treated and cured" (Parent No.11).*

Financial and caring burden: Almost all parents voiced about the financial and caring burden. Parents expressed that it was a mammoth task to take care of autistic children as they were incapable of self-care. Everything had to be done by caregiver, which required parents to be always available in caring for the Children with ASD. Along with taking care of autistic children, mothers had added responsibilities of caring for the rest of the family members like siblings of the ASD child, husband and any other people in the family. Thus, the mother felt overwhelmed and overburdened in caring for the whole family.

> *"The most serious challenge weighs heavily on the person who takes care of him, for a child with autism has no sense of cleanliness; He is very dirty. On taking a look at his clothes, you find them too dirty to ask anybody to wash them. At times I feel like helping the housemaid, but I do not manage to do so because I happen to be worn out/very tired. It is not easy to take care of him because he does not stay in the same place" (Parent No.08).*

Parents interviewed in this study expressed that ASD services in Rwanda were too expensive and unaffordable. The ASD services include health care services, home care and special education. Home care of autistic requires one to hire an additional housemaid for caring the ASD child.

> *"My resources to take care of my child are not enough especially when it comes to special schools meant for autistic children. Schools of this kind are very expensive. In addition, we have to look after his siblings. So, we had better get another housemaid specifically assigned to take care of this child which is not affordable. Look! How many housemaids can we bring in here and ensure their wages?" (Parent No. 18).*

Considering the behaviors and a huge effort required in minding the ASD child at home, mothers felt the necessity to take the task into their own hands. As a result, some parents gave up their professional careers, thus decreasing their financial contribution to the household.

> *"It is not even easy to think of getting a job because your child is prone to either ill-treatment or beating by housemaids. So, I find myself with a need to stay here at home to take care of him for the housemaids cannot tolerate his behaviors. Currently, I no longer set out to work to make money. I want to be available to take care of my child"* (Parent No. 4).

Most parents, voiced that children lacked daily living skills (independent personal hygiene), which resulted in the low participation of parents in income generating activities. "Parents are not able to leave their homes due to caring responsibilities for their children with ASD. Thus, parents do not have significant amount of time for paid jobs and any other social activities".

Stigma and discrimination: A large number of parents expressed that they were stigmatized and criticized by community because of the unacceptable behaviors of the ASD child. Mothers of children with ASD are blamed by the neighbors and families stressing that the mother contributed to her child's condition.

> *"However, the community judgments about the family having ASD child, are related to community beliefs regarding the cause of autism and other mental problems. For your information, my family members do not believe in autism and blame my wife for it. They relate autism to poisoning by brothers, sisters or neighbors. People's beliefs are different and depend upon their place of origin. This state of affairs causes stigma within both our own family and the whole community at large even if they do not state it openly". (Parent No. 01).*
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> Parent No18 added: *"The society does not know much about autism; people do not understand it. For example, when they find me with my son walking along streets, they observe his behaviors and conclude that we have educated him poorly. They ask questions as to why we do not punish him. We are blamed for seeming poor discipline our child".*

Almost all parents uttered that the Children with ASD are unaccepted, both by the community and the family (both extended and nuclear families). Peers, teachers, siblings, fathers and extended family members express the non-acceptance attitudes on Children with ASD. A mother with an ASD child has this to say about the father of the child and family;

> *"My spouse is unhappy about the state of affairs. He is not comfortable. I try my best to encourage him by explaining to him that there is no any other option open to us for the good of our child because there is no schools for his special needs. It is true that men do not express their feeling easily, but, obviously, he has a concern about having an autistic child. Similarly, I have realized that my family members find it shameful having such a child in their ranks. Thus, my husband gets frustrated at having an autistic child (Parent No. 4).*
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> *Parent No 19 corresponds: "Once upon time, he was blamed at school. They did not know that I was his mother. This occurred when they wanted to switch over to another class. They stated that my child's behavior was due to the way we had educated him".*

A family is discriminated or stigmatized such that family functioning is significantly impaired. Again, this leads to parental self-stigma, as observed in parents forbidding their children to interact with other children or attend celebration parties in the community. Owing to their disruptive behaviors and misunderstanding of their condition in the community, the Children with ASD are locked up in their homes, due to parents' embarrassment. This results in social isolation.

> *"I do not allow my neighbors to see my child which is not the case when it comes to my family members who can see him. Why should persons from elsewhere have an opportunity to set their eyes on my child? I have been, psychologically, affected by the judgments of the community towards my child and family. I am proud of my child as I can walk with him. I cannot bring my child in parties organized by neighbors. He only attends family parties (Parent No.03).*

Parents feel ashamed of an ASD child because of stigma and negative beliefs people hold against children with ASD. A parent aired out that people do not want to sit with them and sit at a distance from them at the hospital, fearing that their child is demon possessed.

> *"When I take him to hospital everybody runs away from us apart from those who are fearless and dare to enquire from us as to whether or not we have taken him to hospital before for medical assistance. It is feared that he may be possessed by demons as they have been saying. Anyway, I do understand their attitude to some extent because this is an unusual condition they have ever come across. This stigmatizing attitude brings me a big shame due to having a child with autism" (Parent No.18).*

Lastly, parents expressed that it was difficult to point out stigma and discrimination evidences held by the community as any forms of exclusion, since law, in Rwanda, prohibits this. For instance, parents stated that the community had stigmatizing attitudes towards Children with ASD but it is not apparent discrimination.

> *"There is no stigma perpetrated to us but they can do it and do not express it openly as exclusion or discrimination is prohibited by law and can be condemned in Rwanda" (Parent No. 17)*

Challenges faced by clinicians managing Children with ASD

Minimal knowledge regarding ASD: Findings from this study highlighted that clinicians in different health care facilities, are ill prepared and ill equipped with adequate skills for management of Children with ASD in need of ASD services, as expressed by clinician No.18:

> *"Unfortunately, I am short of knowledge which is required as far as autism is concerned" (Clinician No.18).*

In addition, ASD can be mistaken with childhood depression, anxiety and mental retardation due to the overlap of certain symptoms, owing to lack of knowledge, as uttered by clinicians. The limitation in knowledge hindered the management of autistic children.

> *"there are many other diseases that can be confused with autism due to limited knowledge" (clinician No. 16).*

The clinicians expressed deep *frustration* related to the unavailability of ASD treatment. For example, one clinician was frustrated by his incompetency in managing Children with ASD, yet parents came with high expectations on them to treat their children.

> *"Imagine! Parents turn out here with certainty that I am able to treat their autistic children. The inability to meet their expectations brings a big shame on me and I am profoundly frustrated at it" (Clinician No.01).*

Overwork: The clinicians complained of overwork, stating that Children with ASD management was excess responsibility, time consuming and stressful. The other clinician voiced that autistic children needed special attention and permanent observation whilst at the same time, they had to manage many other psychiatric children within the unit. The shortages of clinicians also contributed to the overwork.

> *"The challenges that we are faced which arise from the shortage of professional staff by the time when there is a big number of children who are admitted here. So, caring services are not properly provided as I find myself overworked" (Clinician No.14).*
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> *Clinician No 5 augments: "First of all, it was very difficult to me due to autistic children's behaviors that call for special attention. Children with autism cannot be engaged in a given activity and perform it together due to lack of concentration and interest. In addition, they do not ask any question for more details. This was very difficult to me and time consuming".*

Social interaction barriers: Clinicians mentioned that social interaction barriers are a major challenge related to ASD condition. In this, the clinician accents that it is difficult to manage autistic children, as they are unable to neither communicate nor interact with others in their environment. However, group therapy had proved to be effective in managing relational problems.

> *"It is very difficult as children are disconnected from the reality around them. Therefore, it is not easy to communicate or have any other form of relationship with them. However, groups of patients help to change their behavior or any other symptoms of their sickness. Furthermore, a child with autism cannot interact with others which is a stumbling block to the effort to take care of children/adolescents with autism. It really makes me work hard as a child with autism requires a special and permanent attention by the time when there are other children in need for our assistance", (Clinician No.03).*

Social interaction was communicated as a valuable method used by clinicians in managing Children with ASD. Not only is it important for autistic children but also on any other mentally ill persons. The success of any kind of therapy involves interaction between professionals and patients. The patient should be involved in the whole process of therapy, starting from goal planning to the end therapy.

Theme 2: Coping strategies adopted by parents and clinicians for caring for Children with ASD

Coping strategies adopted by parents for caring for Children with ASD

Although participants in this study articulated major challenges faced in caring for Children with ASD, the participants indicated possible coping strategies that could be adopted to overcome these challenges faced. The coping strategies are acclaimed for facilitating resilience and caring processes. Coping strategies adopted by parents of Children with ASD generated different useful information necessary in taking care of their Children with ASD. These include;

Self-informing: Parents 06 and 18 opted searching ASD related information on internet which provided them the ASD diagnostic criteria and its possible management. The same participants revealed that internet based search offered them an opportunity to compare their children's symptoms with the clinical cases which were displayed on internet.

> *"It was my first time to hear about autism. I was advised to surf the internet to get more related information. From this search I got to notice similarities between the symptoms on the internet and those ones which had manifested themselves with autistic children", (Parent No.18).*

In a bid to overcome the issue of inadequate knowledge about ASD, parents undertook self-informing as strategy to equip themselves with knowledge, competencies and skills needed for caring for autistic children. In addition, consulting other parents (parents' group) contributed to the process of increasing ASD related knowledge and information. According to parent 12 point of view, the parents' association was an opportunity for them to share experiences related to symptoms and methods of caring for autistic children. In addition, parents expressed to have consulted the extended family members (child grandparents or another important figure in the absence of grandparents) for ASD related problem solutions.

> *"We do not have any mastery of the problem we are faced with. One gets aware of it as time goes on to, eventually, take an action. By the time when I was told of this problem, only a couple of cases of autism had been identified. I thought of getting in touch with other parents for us to put in place a platform aiming at exchange of information. There was a little information about autism in terms of awareness and the approximate number of parents with autistic children (Parent No. 01).*

Respite services: Parents consider respite services as an alternative solution in caring for autism. According to parents, the respite services included; day centers or day special needs schools where parents believed to receive better educational assistance for their children. Thus, parents have time for income generating activities or searching for a job for self-development and taking care of their other family members.

> *"He was the only one child that we had by that time. Therefore, staying at home alone was the most daunting problem to him. To solve it, we embarked on a strategy which consisted of creating opportunities likely to bring him together with others. We tried to find him a school that could help him to socialize with other people. We managed to find HVP Gatagara rehabilitation center that accepted to enroll him" (Patient No.06).*

Reliance on God's power and traditional healers: Almost all parents considered prayers as a powerful means to increase parents' resilience and improve the quality of their relationship with God who decides everything in their life. Although the majority of parents believed that ASD had a medical etiology, they mostly held the belief of the Supreme Being's will, in the justification of their child's condition. The reliance on the Supreme Being will is the natural explanation of the ASD condition that compelled them to seek God's assistance to resolve their child's problems. Also, advised by extended family members or not, some parents expressed to have been consulting traditional healers for assistance in ASD care.

> *"We are Christians. We believe that prayers can help us to accept our child and live with him. As we know, God is powerful and able to solve every problem. Only God knows our needs and provides solutions (Parent No.12).*

> *Parent N. 16 complemented: My child taught me how to pray. I could, moderately, attend prayers, but nowadays I go to pray regularly. I have consulted all famous preachers in Rwanda. I have met them in quest for assistance. They have been saying their prayers and are convinced about the power of these prayers to help my child recover from autism. They have even produced to me a number of testimonies to the fact that a big number of people have recovered due to prayers.*

Acceptance: Lastly, parents expressed that, accepting their child's condition proved to be the best way coping with ASD related challenges and in dealing with the situation at hand. Parents 02 and 08 vented that they gained resilience to move forward, through accepting their children's condition.

> *"The paramount coping strategy was all about accepting such an unpleasant condition of my child. This has helped me a lot. Before, I was shocked and found it hard to accept that condition. Now that I have accepted that condition, I am feeling very well", (Parent No.08).*

> *"When I learnt that my child had autism, I got shocked about that condition because I could not do anything else or change it. Despite this, we are leading our life as usual" (Parent No.02).*

Acceptance helps Children with ASD' parents by reducing any ASD related emotional problem. It also aids in overcoming challenges of disappointments due to failures in finding remedy after hard-wearing efforts of seeking remedy. Thus, acceptance contributes positively to the ASD child care, as well as involving other family and community members in care for the ASD child.

Consulting family members and clinicians in health care facilities: parents verbalized that coping with issues related to ASD, involved consultation with family members both nuclear and extended family as other family member behavior or problems is a concern of the family in general. In sub-Sahara African generally and in Rwanda, families are seen to influence individual's life decision. Also, parents expressed that clinicians at different health facilities assist them to cope with ASD related issues.

> *"I took him to health facilities, we had information from others that there is a doctor of Ear, Nose and Throat (ENT) who consulted child and found no problem on respiratory system. After we took him to another health facility which prescribed medication without success. When we were preparing ourselves to take the child to Faysal Hospital, we were informed that Kanombe Hospital took care of such children", (Parent No.08)*

On the other hand, another parent aired out that the family members assisted her in finding solutions to her child's behavior, thus helping her to cope.

> *"In my family I talked to my elder brothers, my wife's father, not living in same place as us. We explained the problem that our child had and they oriented us to people who could help us to change our child's behavior to normal behavior like other children. We took and considered every one point of view but without immediate implementation of their ideas", (Parent No. 09)*

Coping strategies adopted by clinicians for managing Children with ASD

Self-informing: Clinicians communicated that they relied on literature and internet based search as tangible sources for increasing the knowledge and skills of ASD management. A clinician managing Children with ASD supplemented his knowledge regularly by consulting literature and online resources available within Care unit.

> *"Autism related knowledge is still insufficient, but I am searching both in books and on internet to get relevant information about autism management", (Clinician No.09).*

Team work: In addition, Clinicians articulated involvement in consultation with their colleagues in ASD management, as a coping strategy in increasing their knowledge and skills. It is considered as the extensive and permanent solution in overcoming challenges or any other problems met in managing Children with ASD in the Care unit. Consulting with colleagues within a multidisciplinary team provides important practical advice and guidance when faced with difficulties in care, as uttered by the clinician 33;

> *"My coping strategies include sharing information with my colleagues about my client so that we can make a mutual decision as to what we should do to help the client. So when I have a problem I share information with my colleagues and we find a solution together", (Clinician No.03).*

The support offered by colleagues plays a significant role in clinicians' adjustment, considering management of autistic children, assigned to them as referent nurses or psychologists. This team work may be assembled through different opportunities obtained during a set of activities that take place within their institution. Along with interpersonal consultation, most clinicians reported to have been involved in meetings at Unit level and clinical supervisions. These meetings staged an opportunity to discuss and seek a piece of advice or guidance on how to manage and overcome the difficulties faced when caring for an ASD child.

3.5. Discussion

The current study describes challenges faced and coping strategies in caring for Children with ASD in Rwanda for both the parents and clinicians. Findings from the current research generated new information to literature about lived experiences, of parents and clinicians in caring for ASD children in Rwanda. Both the parents and clinicians shared a mutual challenge of lack of knowledge in the care of Children with ASD as well as frustration that comes with overburden characterizing the care. Moreover, self-informing technique was considered as a common coping strategy adopted by both groups.

With reference to challenges, the limited knowledge amongst clinicians was also articulated by parents of ASD's children, who perceived some degree of confusion and poor appreciation of the ASD amongst clinicians. Complementing this is the clinician's statements, harmonizing to that clinicians had insufficient knowledge and skills to effectively manage Children with ASD. Again, the clinicians honestly disclosed to the parents that there was nothing else they could do for the child with ASD. They would then advise parents to take their children back home or look for respite services (special schools). Thus, parents became frustrated and worried about the future of their children. Yet, in the same vein, the clinicians themselves were equally frustrated due to the limited knowledge and competency skills, minimal tools and protocols specific for the management of Children with ASD.

It is apparent that the clinicians were frustrated by their incompetency that was also displayed in front of the ASD parents who expected them to treat their children. Some clinicians would either abandon the task of managing the ASD child or refer to another colleague. The Findings of this study with regards to limited knowledge and frustration of clinicians were similar to findings found in Asia by Minhas and research team (2015) and WHO report in 2014 demonstrating the poor awareness and inadequate knowledge about ASD condition among front line health care providers, which resulted in inappropriate management of ASD (WHO, 2013).

This study demonstrated that home care was challenged by stigma of ASD child, financial and caring overburden. Parents reported shame and isolation of their families and Children with ASD due to community's intolerance and negative judgments. Another study however, hinted that the child's comprehensive home-based services had been terminated because of the child's hostile behavior (Giovanni et al., 2020). McCafferty and McCutcheon (2020) concur by highlighting ASD consequences within the family as family isolation, loneliness and guilt. In Africa, stigma is strongly related to the lack of knowledge or and information about ASD in communities where the family with autistic child lives.

There is a strong belief that ASD is the end result of the mother's previous prohibited cultural actions before getting married (Cloete & Obaigwa, 2019; HA, 2018). Also, supernatural powers or family malpractice of prohibited cultural actions are believed to be the cause of ASD (Cloete & Obaigwa, 2019). This misconception is based on spiritual and cultural believes due to the inadequate information held by communities about the causes of autism (Gona et al., 1874). However, this is inconsistent with this study where most parents attributed to the will of God almighty as cause of ASD and to a lesser extent to biological etiology.

This study revealed new information in relation to public hidden stigma and parents' self-stigma as reported by parents of Children with ASD, not reported by almost similar other studies done in Rwanda. It is interesting to note that hiding negative attitudes towards Children with ASD expressed by parents in the study findings, contrast the Rwandan and International Laws against any form of discrimination (Rwandan Government, 2010; United Nations[UN], 1995). In Rwanda, the genocide resulted from discrimination of one group to another leading to national shame, thus the problem of discrimination became very sensitive. It results in social desirability bias, in such some community inhabitants may choose to hide negative attitudes towards Children with ASD rather than risk exhibiting exclusion and discriminative behavior (Baziga, Gasovya & Uwingabire, 2020; Kopera, Suszek & Bonar, 2014). Thus, current literature asserts that such behavior would be influenced by the unconscious conflict between laws, ethics code and personal values and beliefs (DiFranks, 2008; Kopera et al., 2014).

ASD influences family dynamics resulting in parents' overload and frustration in caring for ASD child, especially to mothers who are more involved than fathers and who are just psychologically affected by these concerns mentioned (McCafferty & McCutcheon, 2020; Rankin et. al., 2019). This is consistent with this study, which detailed that parents complained about expensive ASD services especially education for Children with ASD as tuition fees was very high in schools that enrolled Children with ASD. Moreover, parents viewed ASD condition as a cause of poverty in families as some mothers sacrificed their careers with the purpose of taking care of their child suffering from ASD condition. Also, these findings are consistent with local and international investigations carried out in Malaysia by Chu and colleagues (2020), in Ghana by Agyekum (2018) and in South Africa by Reddy and colleagues (Reddy et al., 2019).

Clinicians underlined overworking and social integration barriers in this study. They expressed social integration barriers with Children with ASD as major challenge in caring for these children who lack capacity to communicate and interact with their environment. Clinicians ushered in new information for current literature in Rwanda by qualifying ASD as overloading them, since Children with ASD's disruptive behaviors needed special attention, at a time when the Care Unit was under-staffed in proportion to the number of children admitted there.

Furthermore, this study determined the parents' and clinicians' coping strategies in caring for Children with ASD. In relation to coping strategies, this study added new information to the current literature in similarities between parents and clinicians' coping strategies related to ASD care. For example, self-informing was adopted by almost all clinicians and parents as a coping strategy in overcoming the challenges of inadequate information in ASD. As far as it self-informing is concerned, internet based search and reading available books were commonly used by clinicians and parents to acquire information on the causes and management of ASD.

Findings from this current study are in line with the study conducted in California - USA by Nefdt (2010) suggesting that self- training of parents having children with ASD would play a significant role in improving behavioral patterns of both parents and their autistic children. Grounded theory, a qualitative study, conducted in Canada by Gentles and colleagues augmented self-informing as a method used by parents for increasing knowledge and the level of understanding of ASD related challenges (Gentles, Nicholas, Jack, McKibbon & Szatmari, 2019).

To blend this, clinicians adopted team work through consultation with colleagues to overcome challenges witnessed during the process of caring for the Children with ASD. Colleagues' support is harmonized by Cloete and Obaigwa (2019), where peer learning and interpersonal collaboration are demonstrated as helpful through sharing living and working experiences which enables them to meet a number of challenges (Cloete & Obaigwa, 2019). Similarly, multidisciplinary team work provides therapeutic ASD services as emphasized in the study conducted by Sinai-Govrilov and colleagues (2019) in Israel. Peer learning amongst multidisciplinary team members was demonstrated to be advantageous in this study as well.

This study showed that parents were confused and distressed in caring for the Children with ASD, which then motivated them to search for the appropriate respite or remedial care as a measure to effectively care for the Children with ASD. Such findings are similar the studies conducted in Africa (Kenya) (Cloete & Obaigwa, 2019), in Asia (Pakistan- India) by Minhas (2015) and in Europe (Ireland) by Cooke and colleagues (Giovanni et al., 2020). In these studies, parents displayed interest in respite facilities for children with ASD.

Parents seemingly relied on supernatural powers and acceptance as coping strategies. Although parents relied on supernatural beliefs (Christian faith and traditional healers), these are not free from misconceptions regarding ASD. However, they are considered by some parents and their families as a good source of coping strategies to overcome challenges of ASD. These findings coincide with African and international studies. For, instance Ghana (HA, 2018) and Kenya studies (Cloete & Obaigwa, 2019) presented that parents trust prayers and traditional practitioners for advice, support and guidance. The similar findings were revealed in the study conducted by Chu (2020) in Malaysia and in south Asia (Pakistan &; India) (Minhas et al., 2015). These studies suggested that prayers and traditional healers largely influence the beliefs of parents with Children with ASD. Participants revealed that it was helpful to take part in prayers especially when it comes to accepting ASD condition (Minhas et al., 2015). Thus, parents become psychologically stable, reducing stress or distress related to ASD condition.

Importantly, the current study engenders new information into the literature on involvement of the extended family as a coping strategy, represented by grandparents or any important figures in the extended family (chief of family if applicable).

3.6. Conclusion

To conclude, the current study clarified daily experiences with respect to challenges and coping strategies on the part of parents and clinicians who are in contact with Children with ASD on permanent basis. The researcher's findings inform the Rwandan political and health decision makers for integrating ASD related issues into national agenda. Also, outcomes of the current study support in service training of health professionals and integration of ASD courses into curriculum of health professionals' education. Lastly, raising awareness of ASD condition in families and communities could play a role in increasing knowledge about Children with ASD and alleviating Children with ASD related overburden and stigma. Therefore, parents will benefit emotionally and psychologically. This would be of great assistance to family members as well as improve Children with ASD' life condition and health outcomes. For the future, further studies may take an interest in evaluating siblings', extended family members', neighbors', political, health and education decision makers' perspectives of Children with ASD as well as the cultural and traditional perspectives of ASD.

3.7. Limitations

The present study involved small sample size (20 parents and 20 clinicians) thus views about challenges and coping strategies were specific to the small group participants and consequently did not represent views of parents having children with ASD in Rwanda who did not participate in this study. Therefore, parents training is needed to reduce challenges faced by them. However, cultural stigma and funding challenges are observed in hindering the implementation of parent training (Chu et al., 2020) . Along with small sample, the study was conducted in Kigali city parents only, thus restricting the generalizability of the findings to the broader Rwandan population. Regarding clinicians, the sample is dominated by professionals working at National psychiatric hospital and Kigali teaching hospital. The health centers and district hospital were not represented, thus making the findings ungeneralizable to Rwandan Health professional.

There were fewer numbers of fathers reflecting that mothers are primary caregivers and much more available for the Children with ASD care. Future studies to involve fathers at the same level as mothers for their experiences about the ASD childcare to determine whether their experiences are similar or different. Most of parents interviewed were caring for a boy with ASD that was not complying with the sex ratio in current literature (Fombonne , 2005). The sex ratio in the current study was one girl to eight boys while it is necessary to observe how the gender of ASD child affects behavior of parents and family in general. The primary diagnosis of ASD as discussed in DSM 5, states that, different subtypes and children may have different ASD categories (simple, moderate and severe) that may affect parents' behavior differently. More researches are needed to explore how subtypes and categories of ASD affect parents to children with autism

CHAPTER IV: A PILOT AND FEASIBILITY RANDOMIZED CONTROLLED TRIAL OF FAMILY FOCUSED TRAINING THERAPEUTIC MODEL FOR ASD IN SSA (FASSA)

4.1. Introduction and background

Screening and diagnostic tools enable health professionals and parents to recognize and confirm ASD. In the light of recent literature both identification methods for ASD at early developmental stages and early intervention methods are the best ways of improving the outcomes of ASD and the well-being of Children with ASD (APA, 2013; Gitimoghaddam, Chichkine, McArthur, Sangha & Symington, 2022; Harrison, Weber, Jakob & Chute, 2021). Typically, autism occurs in the course of developmental stages with difficulties in relationship along with constricted and persistent behaviors, enjoyment, or routines (APA, 2013; Gitimoghaddam et al., 2022; Harrison et al., 2021). However, these therapeutic interventions were initiated in west, thus, their adoption and implementation in developing countries is challenging. The current literature depicts several early interventions for ASD developed by scientists and supports the effectiveness of behavioral interventions throughout Children with ASD's life span. The researchers claim that, applied behavior analysis (ABA) and Naturalistic Developmental Behavioral Interventions (NDBIs) are efficient and have positive impacts on ASD outcomes on children's behaviors (Gitimoghaddam et al., 2022; Reichow et al., 2018). ABA, psychological principles of learning theory, when utilized, bring about a shift in observed behaviors. The changes are; restructured thinking and reasoning, speech skills, and adaptation skills (Gitimoghaddam et al., 2022). ABA based interventions consists of very well structured training of infants as well as high expertise and teaching skills of health professionals (Moulton, Bradbury, Barton, 2019; Reichow et al., 2018; Schreibman et al., 2015).

The ABA interventions concentrate on specialized therapy for infants (Landa et al., 2011; Mullan et al., 2021). Child outcomes are taken in consideration in evaluation of the interventional programs for the caring of autistic children. Naturalistic approaches involve naturalistic and interactive social context, providing an opportunity of play and use of daily routines. They employ high training skills, adequate and required skills in natural environment, involving strategies interesting family members, and have emphasis on parent facilitation aspect with sessions undertaken at the client home, the NDBIs are considered as reference models because they involve parents providing training in home settings (Schreibman et al., 2015). Again, the NDBIs comply with the current Rwandan Health care system that rely on community based psychiatric services and decentralization of mental health services into PHC (Rwandan Ministry of Health, 2011, 2013, 2018). The recommendation of NDBI with regards to ASD, is in line with WHO and developed countries' policies. Thus, these policies recommend community based approaches to handle health related problems in mental health care, orientation and interactions with families (Ait Mohand, Kayiteshonga, Misago, Dusabeyezu & Iyamuremye, 2017; Rwanda Ministry of Health, 2018). Hence, services are performed closer to the communities and families or within families, continuously and comprehensively. The mental health care system in Rwanda applies the NDBI principles as evidenced by decentralized health services to the community health facilities. In communities (villages), health professionals are directly in contact with community residents and families (Ait Mohand et al., 2017; Rwanda Ministry of Health, 2018).

These approaches allow parents or family members of the child with ASD to take part in ASD interventions as they live together and share everyday life in the family routines (Schreibman et al., 2015). Thus, the family becomes the primary accessible and affordable agent of respite services as parents expressed this issue among challenges and coping strategies for caring for Children with ASD (Reddy et al., 2019). Furthermore, these interventions involve parents as intervention mediators (Rahman et al., 2016; Schreibman et al., 2015). The naturalistic approaches involving home were implemented in LIC, MIC and HIC, and thus, they have been adopted and deemed appropriate in cultural contexts. For example, studies conducted in India and south Asian countries engaging parents as home therapists, displayed effectiveness in feasibility for amelioration of deficits caused by autism (Manohar et al., 2019). Also, a systematic review and meta-analysis of parent-mediated interventions for children and adolescents with autism spectrum disorder in Mainland China, Hong Kong, and Taiwan reported on the efficacy of these interventions (Liu et al., 2020). As described throughout the general introduction (page 25-26), home based intervention involving parents showed improvement of ASD symptoms with medium and large sample sizes. In the current global health context, the present study made a systematic cultural adaptation of a treatment of ASD, which was developed and evidenced in LMIC (India in Asia) and its effectiveness tested in SSA countries, where the most of them were categorized in the same class with India. The Asian treatment is called Parent Mediated intervention for caring Autism Spectrum Disorder, conducted in South Asia, India; and the researcher's adapted intervention called Family focused training intervention care model for caring for Autism Spectrum Disorder in Sub-Sahara African (FASSA). Parent Mediated intervention in caring for ASD children was selected because it is conducted in family settings by parents and was considered appropriate to the LMIC context where African countries are classified.

Components of the adapted model (FASSA)

The FASSA focuses on psycho-education, joint attention, imitation, social skills and adaptive skills. (1) ***Psycho education*** is defined as the education of a patient with mental illness about the psychiatric symptoms, treatment, management, and prognosis of that mental illness (Alhadidi et al., 2020; Casañas et al., 2019; Tabeleão et al., 2018). FASSA equips families of children with ASD, with knowledge on ASD etiology, symptoms, coping strategies with ASD and its outcome. (2) ***Joint attention*** is an ability to share focus on an object or area with another person (Nyström et al., 2019). Examples of joint attention skills include following someone else's gaze on pointed finger to focus on something (Nyström et al., 2019). The joint development, attention, or initiating joint attention is related to language skills in both non autistic children and autistic children (Kasari et al., 2010; Nyström et al., 2019). Joint attention provides opportunities to improve both verbal communication and non-verbal communication as it facilitates learning by imitation (Schreibman et al., 2015). Ingersoll and Schreibman, as well as Kasari and colleagues showed that joint attention based interventions, in children with ASD contribute to positive changes in social and communication behaviors in addition to improvement in joint interaction and have thus recommended joint attention as a pivotal component of the early intervention (Kasari et al., 2008; Schreibman et al., 2015). ***(3)*** FASSA also emphasizes imitation, which is crucial for learning and social acceptance since it allows children to interact with other family members. (Schreibman et al., 2015). Therefore, children can learn from others, like adults, siblings and peers. Again, imitation enables social interactions of children with others including parents, siblings and peers as well (Killmeyer et al., 2019). Current literature on NDBIs narrates the effectiveness of learning through imitation in social engagement (Ingersoll, 2010; Ingersoll & Schreibman, 2006; Landa et al., 2011). ***(4) Social skills;*** FASSA aims at improving the proximal socio-communicative skill deficits as part of early behavioral intervention, and it met the demands of the study population. A social skill is any competence facilitating interaction and communication with others where social rules and relations are created, communicated, and changed in verbal and nonverbal ways (Dekker et al., 2019). ***(5) Adaptive skills training***; while Western modules predominantly focus on joint attention and communication skills, emphasis on adaptive skill training is a unique need in our setting. As a result, systematic adaptive skill training based on the child's developmental stage is provided. (Rahimabadi, 2015). Adaptive skills are defined as practical, everyday skills needed for functioning and meeting the demands of one's environment, including the skills necessary to effectively and independently take care of oneself and interact with other people (Rahimabadi, 2015).

4.2. Aims of the study

1. To examine the attrition and attendance rate of the research participants during the family focused training therapeutic model for ASD in Sub-Sahara Africa in Rwandan context.
2. To investigate on children with ASD’s families with regard to their compliance with the family focused training therapeutic model for ASD in Sub-Sahara Africa in Rwandan context
3. To evaluate whether there is a significant difference in score on CARS-2 and CASD between the Children with ASD who receive the family focused training therapeutic model for ASD in Sub-Sahara Africa in Rwandan context and those who do not receive the treatment.

The present study aimed at clarifying the question whether (1) the families had good or poor attrition and attendance rate during the FASSA in Rwanda; (2) families of children with ASD were compliant with FASSA or not, in Rwanda; and (3) there is difference in symptoms reduction between the Children with ASD who received FASSA in Rwanda and those who do not receive the FASSA in Rwanda.

4.3. Hypothesis for study 3 (chapter IV)

Considering some of the previous research finding(Anker et al., 2009; Bringhurst et al., 2006; Deb et al., 2020; Duncan et al., 2003; Manohar et al., 2019; Perera et al., 2016; Pickles et al., 2016), hypotheses are as follows:

Hypothesis 1: The training session rating score will be improved after every rating session in intervention group

Hypothesis 2: The children outcome rating score will be improved after every rating session in intervention group

Hypothesis 3: The ASD symptoms in participants allocated in intervention group will be reduced in comparison with the participants allocated in control group after the overall FASSA intervention

Hypothesis 4: The ASD symptoms of participants allocated in intervention group will be reduced at the end of therapy and follow up compared to the baseline.

Hypothesis 5: There will not be reduction of ASD symptoms of participants allocated in control group at the end of therapy and follow up compared to the baseline.

The table below displays a summary of hypotheses for the study three and the expected observation.

Table 10.: *Summarized list of hypotheses study three*

H	Assessment	Group	Expected observation
1	Session 1–5	IG with TAU	↑ SRS
2	Session 1–5	IG with TAU	↑ CORS
3	Baseline, end therapy and follow up assessments	IG with TAU & CG with TAU	IG (reduction in mean score on CARS & CASD) CG (no change in mean scores on CARS-2 & CASD)
4	Baseline, end therapy and follow up assessments	IG with TAU	Reduction of ASD symptoms on mean scores of CARS-2 &CASD between baseline, end therapy and follow up assessments
5	Baseline, end therapy and follow up assessments	CG with TAU	No change of ASD symptoms on mean scores of CARS-2 & CASD between baseline, end therapy and follow up assessments

Note. H - hypothesis; IG - intervention group; CG - control group; TAU - treatment as usual; SRS - session rating scale; CORS - children outcome rating scale; CARS2 - childhood autism rating scale- version 2; CASD checklist for autism spectrum disorder; ↑ increased.

4.4. Materials and Methods

The research materials and methods section is the plan that will be undertaken by the researcher to conduct research investigations (Burns & Grove, 2009); thus methods section discusses the process of the study.

4.4.1. Research setting

The research settings included 2 referral hospitals in Kigali city, CHUK and Ndera Psychiatric Hospital, community homes of 3 Kigali districts, which are Nyarugenge, Gasabo and Kicukiro districts, and 5 Provincial districts, closer and less than an hour's travel to Kigali city, Kamonyi, Muhanga, Gakenke, Gicumbi and Rwamagana districts. In addition, special needs schools, Autisme Rwanda and HVP GATAGARA de Gikondo in Gasabo and Kicukiro districts respectively, were used as research settings. The home communities and special needs schools facilitated the researcher to contact and meet parents of Children with ASD.

CHUK and Ndera Psychiatric Hospital are national referral hospitals for District hospitals where psychiatric patients including children with ASD are referred to, for advanced psychiatric care. Moreover, health services start from health center as explained in health system of Rwanda. Health center provide the essential and basic mental health care, comprising counseling, provision of essential medications; in line with the essential drugs list specified in the (WHO, 2019). Over again, Health centers provide psychiatric services for their respective communities including the special needs schools. CMHs in villages work under the supervision of their respective health centers (Rwanda Ministry of Health, 2013). Other specialized ASD services offered by special needs schools in Rwanda are private and were in Gasabo and Kicukiro Districts. When there is need for advanced care health practitioners in health centers refer patients to district hospitals which in turn transfer clients to Ndera Psychiatric Hospital or CHUK mental health Unit (Rwandan Ministry of Health, 2019). These two, are national referral hospitals in Rwanda which provide specialists psychiatric services (Rwandan Ministry of Health, 2011).

4.4.2. Research population

The population who participated in the study comprised children of 4-12 years of age with confirmed autism, receiving treatment services at public facilities provincial hospitals and special need schools. The diagnostic confirmation was done during the study one by researcher using the two international standardized tools (CARS-2 and CASD) which had good reliability (page 47-48). The autism spectrum disorder frequently has comorbidity, that is, Children with ASD with minor or major psychiatric comorbidity, thus the study included the Children with ASD with minor psychiatric comorbidity that did not take priority on treatment, in a bid to achieve a statistically significant sample.

Inclusion criteria:

- Children with confirmed ASD diagnosis from the study 1
- Children with moderate and severe ASD (LFA)
- Children with ASD with a complete contact address of their respective families and communities/ villages where they were living;
- Children with 4 to12 years old
- Parents and family members who lived with Children with ASD;
- Kinyarwanda speaking parents, accepting participation
- Children with ASD from families who consented for participation and who are living in Kigali city and district closed to Kigali city

Exclusion criteria:

- Known comorbidity with other major, severe and chronic psychiatric/ neurological disorders that take priority on treatments (psychosis/ schizophrenia, major depression and bipolar disorders).
- Children with HFA
- Children with known visual and hearing impairments
- Non-Kinyarwanda speaking participants and the non-consenting;
- Parents, family members with a known profound neurological or a severe psychiatric disorder

4.4.3. Sampling

The sample size estimation was based on the primary outcome "mean differences in the Autism Rating Scale" between the intervention and control group. The primary analysis model was done by repeated-measures ANOVA (Geisser-Greenhouse correction assuming not esphericty), using the following variables, mean value of CARS score between group factor and the repeated within-group factor was time (T0 = before intervention, T1 and T2 follow up) and their interaction. Similar study (ref DOI DOI 10.1007/s10803-016-2936-9) have found a mean of CARS of 32 and *SD* = 5.19, To detect a 14% difference among groups and 5% difference of CARS score within an individual across time, with a power of 80% and alpha level of 0.05, 21 participants are needed per group. The sample size was estimated by PASS 2020. (Muller, Edwards, Simpson & Taylor, 2007; Naik & Rao, 2001; Simpson, Edwards, Muller, Sen & Styner, 2010).

Of ninety-four (94) pre-diagnosed children with ASD, 52 children were excluded from children eligible for intervention due to following reasons; (1) did not meet the inclusion criteria (n=20); (2) declined to participate (n=5); (3) long distance from Kigali city (n=12); (4) were not able to participate due to logistically and scheduling conflicts for consent (n=7); (5) failed to respond to telephonic calls (n=8). When the sample of 42 children was achieved, the recruitment process was ended. Purposive sampling was utilized to recruit the families that participated in this study. The intervention study sample was N = 42 consisting of the intervention group (n = 21) and group control (n = 21). Thus, either child, was assigned to an experimental or to a control group by randomized methods.

A simple random sampling was employed to determine who would be enrolled in control or intervention group. In a box, there were intervention group papers and control group papers and for each ASD child, and a blindfolded person randomly picked a piece of paper which decided the allocation of the ASD child. To save time, the allocation process started concurrently with re-evaluation in progress to confirm ASD diagnoses in children. A parent who consented to the diagnostic procedure for confirmation was requested also if she/he could participate in the next step. After consenting for interventional research, the randomization and allocation of the child in either intervention or control group began. The process of sampling and allocation started on 21 June, 2021 and ended when the sample size 42 families, was obtained (on 30 July 2021).

4.4.4. Procedure and Design

The study design was based on an intervention adaptation approach, established by the Expert Advisory Board (EAB). Participatory planning methods were used to ensure that local expertise and experiences were reflected in the intervention model. Thus, the emphasis was on engagement, enhancing intervention ‘buy in’ from key stakeholders.

Intervention adaptation and planning activities required active involvement of diverse stakeholders and inputs from community practice partners. These were the individuals with direct or indirect interest in the proposed intervention, that is, people who contributed to its execution and management. Experts from the University Hospital of Tübingen, department of children and adolescents’ psychiatry, psychotherapy & psychosomatic, participated in adaptation of the existing evidence based intervention care model.

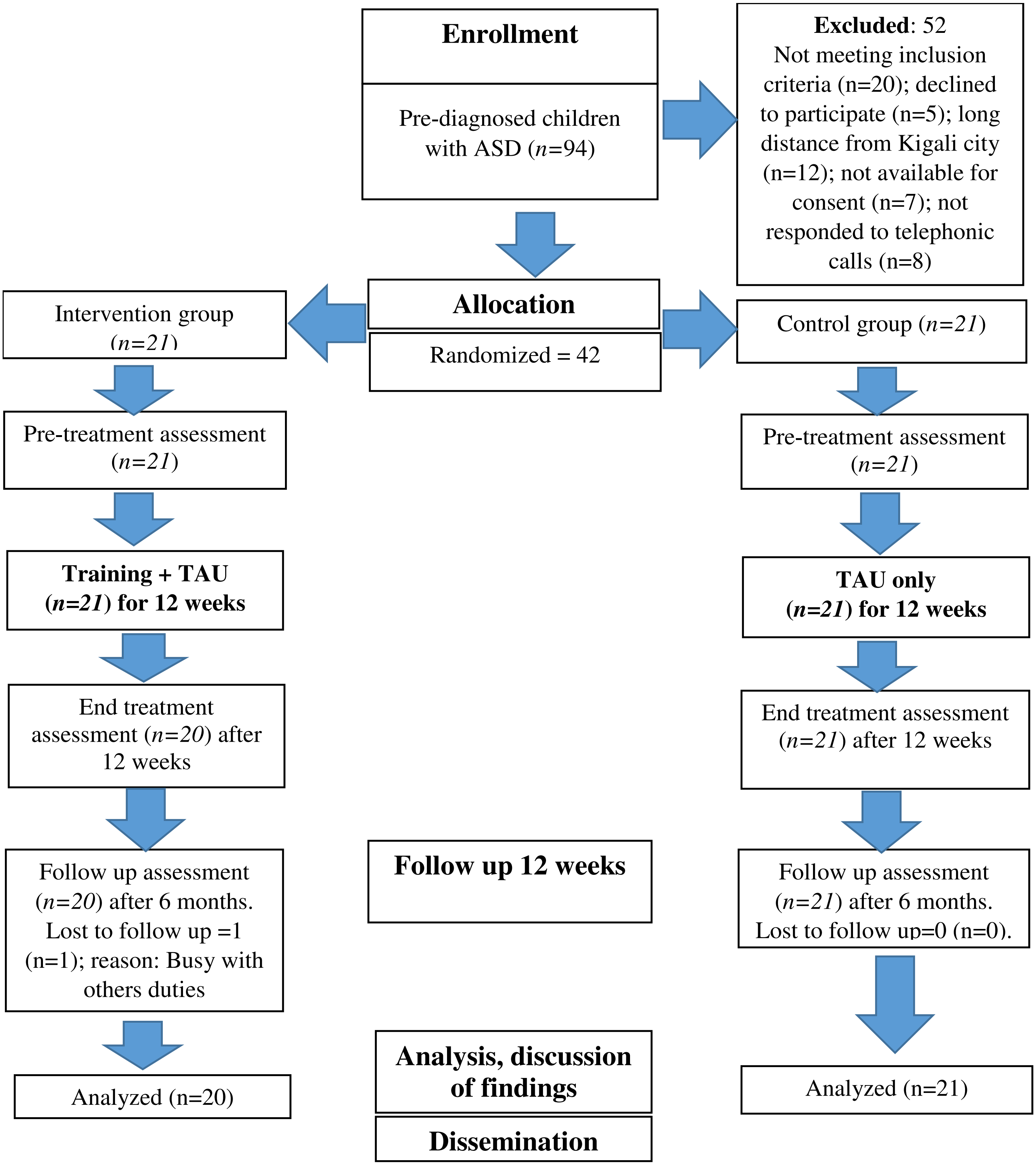
In this study, interventional study design (Pilot and feasibility randomized controlled trial) was used. Therefore, the participants were assigned to an intervention, the family focused training intervention care model for ASD (FASSA) as described in the protocol. The Interventional study model for this study was a parallel assignment. Parallel study is a type of clinical study where there are 2 groups of treatments, A and B. Intervention group A, received FASSA intervention and the control group B, did not receive FASSA intervention. However, a pilot and feasibility randomized controlled trial was adopted instead of the evaluation study since it requires a smaller sample size. Evaluation studies require larger sample size and not feasible where there are limited time and financial resources (Hooper, 2019). In addition, it was the first time for FASSA to be implemented in Rwandan context. In order to gather data on the feasibility of intervention delivery, acceptability of the intervention, recruitment, sampling, and randomization, as well as intervention assessments that inform the researcher's design of a more decisive and adequate randomized clinical trial, a pilot and feasibility randomized controlled trial was necessary (Claire, Gluud, Berlin, Coleman & Leonardi-Bee, 2020; Hooper, 2019).

The pilot and feasibility randomized controlled trial was selected as it allowed the researcher to test whether the major components of the intervention could operate successfully and whether the intervention group had significantly better outcomes than the control group. Moreover, the pilot and feasibility randomized controlled trial was expected to inform the sample sizes for subsequent steps of trial for conducting the extensive or future definitive RCTs (Blatch-Jones et al., 2018; Claire et al., 2020; Eldridge et al., 2016; Hooper, 2019). In addition, the design was selected as it was applicable for trials not involving many people and conducted over a small area and those are miniature of definitive RCTs whereby the primary aim is to assess feasibility and surrogate endpoints/ outcomes (Blatch-Jones et al., 2018; Eldridge et al., 2016). Therefore, the present study complies with these criteria as it was conducted in Kigali and District closer to Kigali only, involved small sample of families and it is preparing for the future definitive RCT covering the entire country and involving large sample of Rwandan families.

Confirmed children with ASD and their families who met the criteria of inclusion, were assigned randomly into intervention group or control group. However, for ethical purposes both groups continued to receive their usual treatment (TAU). Along with training sessions, group for intervention continued TAU while the group for control continued their usual treatment, a usual only. As described in the introductory section (page 31-36), in Rwanda, children with ASD receive care throughout the Rwandan health care system from both public and private health institutions, and at different levels (community, district and referral levels). Screening and diagnosis takes place in Rwandan health facilities, performed by different clinicians including psychiatrists, pediatricians, clinical psychologists and psychiatric nurses (Rwandan Ministry of Health, 2011).

Health services for children with ASD, consists of pharmaceutical or medical interventions for comorbid diseases or symptomatic treatment and paramedical interventions for speech therapy and physiotherapeutic interventions. The management comprises monthly appointments for symptoms evaluation, medication supply, and referral to specialized facilities. The FASSA intervention lasted for 3 months (12 weeks) and consisted of training sessions for each family selected to benefit from the intervention. The duration of the interview was from August 2021 to early November 2021, with 3 months follow ups (12 weeks), from late November 2021 and to early February 2022). The figure 4 displays the intervention study flow from enrollment step to analysis.

Figure 4:The flow diagram of the present study (Pilot and Feasibility parallel RCT)



4.4.5. Structure and protocol of the study

This study revolves around the process of re-evaluating autistic children to confirming the diagnosis of autistic children according to DSM-5 ASD criteria, and child should be receiving services or attended public and private health facilities and centers (district, provincial and referral hospitals in Rwanda). Each child was evaluated at only one-time point of assessment. All re-evaluated children with confirmed ASD and non-confirmed ASD diagnosis continued their treatment as usual, where applicable. Only confirmed Children with ASD were eligible for the adapted intervention.

The parent-mediated intervention for ASD was developed in India. The adapted model was approved by the expert advisory board (EAB). The researcher chose to employ participatory planning methods to ensure that local expertise and experiences are reflected in the diagnostic and intervention care model. The emphasis was on engagement and enhancing intervention from key stakeholders. Eleven individuals comprised of parent representative, staff from non-profit organization, high-level representative from the Ministry of Health/ mental health- policy section, psychiatrist, psychologist and representative of health centre, representative of district hospitals and referral hospitals, lecturer from University of Rwanda and directors of special needs schools were involved in the EAB approval.

The adaptation consisted of developing an adapted intervention care model (materials and protocols) that was presented to the EAB for revision, updating, validation and approval. Some parts of the existing evidence based intervention (Indian parents mediated intervention for ASD) were altered, other interventions were eliminated, whilst incorporating new interventions. This adaptation conducted by EAB consisted of the training manual with training goals, structure and/or protocols of the intervention care model containing number of training sessions, duration, training procedure and training topics based on Rwandan context, as well as the therapist and her/ his professional background. The process of adaptation took one month approximately (May 2020), then followed by its implementation.

The last step consisted of the implementation of the adapted family focused training therapeutic approach for ASD among children in SSA. This step aimed at testing feasibility and acceptability of intervention protocols. Confirmed Children with ASD whose families met the inclusion criteria, were randomized for the trial, and apportioned to intervention group or control group. The intervention involved training sessions that took two weeks and was conducted by the researcher (PI) himself. Participants in the said intervention included Children with ASD, parents, siblings and any other family member. Homework was offered after each training. This intervention lasted 24 weeks, and this included 12 weeks for training sessions and 12 for follow ups, and began in August 2021 to January 2022. Prior to the intervention, there was a pre-treatment assessment (T1) to evaluate the baseline. Then, a follow up evaluation (T2) and a post-treatment assessment (T3) at the end of intervention were performed to evaluate the treatment outcomes.

4.4.6. Blinded outcome assessment

In this study, the researcher involved independent assessors as a strategy for blinded assessment. The researcher adopted this strategy to avoid a systematic variation between the participants' groups (control and intervention groups), which could result in biased estimates of the treatment effect (Kahan, Feagan & Jairath, 2017). This was a blinded outcome assessment; as independent assessors were involved in the outcome assessment. These assessors included experienced clinicians (clinical psychologists and psychiatric nurses) working at district and referral hospitals, with experience in working with Children with ASD. Apart from assessing the outcome, independent assessors did not have any other form of involvement with participants; they were blind towards the treatment allocation (intervention group and control group). The independent assessors, primarily, recorded or judged the outcome so that they could make rating on scales on different occasions for the assessment (Baseline, end therapy and follow up assessments). For this study, the independent assessors used research instruments, which could provide the outcome directly.

4.4.7. Instruments for data collection

4.4.7.1. Assessment methods (battery)

This study was conducted using quantitative methods, which employed semi structured and structured interviews, behavioral observations as well as parents and children's reports. The adaptation of parent mediated intervention for ASD was done by expert advisory board (EAB) and then followed by the study implementation. The EAB assessment included revision and evaluation of materials before the intervention. The researcher conducted the pre-treatment assessment/ baseline, follow up assessment and end of intervention assessment (post treatment) to evaluate the treatment outcomes. Both the feasibility and the acceptability of the treatment were evaluated during the intervention.

4.4.7.2. General measures

As mentioned within the section on methods and materials, the instruments which were employed in the intervention study were valid and reliable. In fact, the instruments in question proved efficient in testing sessions and was done consistently. CARS-2 and CASD were employed as instruments to assess the reduction of ASD symptoms as described in study one (page 35).

4.4.7.3. Measures for feasibility and acceptability

To check irregularities, the consistence of training sessions, attendance and continuous follow up were considered. The irregularities, were recorded and reported to the researcher. These included, among others, the irregular attendance of participants, missed sessions, postponed sessions, delayed sessions, sessions ending earlier than expected, homework non-compliance and dropouts. Moreover, different tools were used to assess feasibility and acceptability.

Home logbook

At home, parents used the home logbook regularly on a daily basis for the purposes of collecting data on attendance rate, consistence of training sessions and the total hours for the whole intervention. To monitor the implementation, a simple home logbook was utilized to record attendance regularity, consistence of sessions, participation rate and time used by the family for the intervention. The home logbook was simple and designed to record parents' educational background, socio-cultural relevance as well as time constraints. Parents were encouraged to complete the home logbook every day, as it could serve as a reminder, ensuring adequate transfer of skills from parents to children.

Session rating scale (SRS) and its validity and reliability

The SRS as a brief and simple scale with 4 items in visual analogue scale model was initiated to evaluate success for therapist and the client relationship. SRS transcribes the perception of the client about the therapeutic alliance on 4 items and a 10 centimeter long, assessing the patient point of view on quality of therapeutic (training) session (Delgado et al., 2017).

SRS was developed in USA as short alternative measures to lengthy research alliance measures (Duncan et al., 2003; Murphy, Rakes & Harris, 2020). Thus, SRS addresses the criticism on the part of clinicians and encourages regular conversations between patients and clinicians with regard to the alliance and progress of the therapy. Research has demonstrated its reliability and validity in various research areas including assessment and management of pain (Delgado et al., 2018; Klimek et al., 2017), quality of care (Arneill & Devlin, 2002), psycho-education (Dannon, lancu & Grunhaus, 2002) and with psychotherapeutic outcomes (Duncan et al., 2003). Moreover, the SRS is regarded as an easier method in the administration and scoring, than other longer and more technical measures/ scales (Duncan et al., 2003). The original SRS was used in western United States for brief psychotherapy approach where the analysis of SRS items found Cronbach's alpha reliability coefficient of.89 (Duncan et al., 2003; Murphy et al., 2020). For current research, the Cronbach's alpha reliability coefficient of .88

Child Outcome Rating Scale (CORS) and its validity and reliability

The CORS was designed for monitoring the children's outcomes, families or reaction on the progression of the therapy. The form was completed by a parent on how the child was progressing. Both SRS and CORS have been developed by Dr. Barry L Duncan and colleagues for client response intervention (Duncan et al., 2003). These tools use the visual analogue scale, (see SRS) to request client feedback and to envisage success of the treatment. That is, the treatment model or the client presenting problem or progression (CORS) and nature of therapeutic alliance (SRS) (Duncan et al., 2003).

Validity and reliability

CORS was used in several studies and revealed reliability and validated scores (Casey et al., 2020). Various validation studies of the CORS were conducted, revealed reliable scores achieved on CORS (Bringhurst et al., 2006; Campbell & Hemsley, 2009; Duncan et al., 2003). The Coefficient alphas was very good as it ranged between.87 and.91 in validation studies and was.82 and.92 in individual therapy and group therapy respectively (clinical studies) (Reese, Robert; Norsworthy, Larry & Rowlands, 2009; Slone, Reese, Mathews-Duval, & Kodet, 2015). Moreover, the ORS was used in RCTs supporting the effectiveness of ORS individual therapy (Reese et al., 2009), family therapy (Anker, Duncan & Sparks, 2009; Reese, Toland, Slone & Norsworthy, 2010) and in therapy group of adults (Schuman, Slone, Reese & Duncan, 2015; Slone et al.,2015). Cronbach alpha coefficient in this research is very good with .95.

4.4.8. Translation procedure

As described in study 1 (page 51-53), the therapy compliance was measured by the SRS and CORS after they had been being translated from an international language (English) into a local language (Kinyarwanda).

4.4.9. Rating procedure

The therapy compliance measures were rated by parents after receiving guidance from the therapist who is an experienced psychiatric nurse specialist and a PhD candidate. As mentioned in the section about general measures, the SRS and CORS have four items rated from 1 to 10 scores for each, which makes 40 scores in total. Parents used at least five minutes to rate therapy compliance measures and the rating was done after each training session, conducted according to their (parents) observations about the training session and the child's outcome. Due to financial constraints and cultural context, training sessions were not videotaped

4.4.10. Calculations and statistical analysis

As mentioned on the section for sample size (page 29), the study sample was 42 children with ASD. Data collection was done using international standardized instruments (SRS and CORS) and home logbook. The home logbook provided information about family attendance and hours spent for a given training session by the therapist (PI) and hours spent by parents or family members during daily exercises within the family circle. The international standardized instruments for therapy compliance were measured on 4 items for both SRS and CORS as described within the section about general measures.

The SPSS was used to analyze collected data. The attrition and attendance rate for families during training sessions were calculated using descriptive statistics (Pallant, 2013). Also, descriptive statistics were utilised to calculate therapy compliance with family participating in the intervention as measured by SRS and CORS. Moreover, one way repeated measure of variance (ANOVA) was executed for calculating differences between training sessions from session 1 to session 5 for therapy compliance (SRS and CORS). The difference in score on CARS-2 and CASD measured in control and intervention groups at end therapy and follow up assessments was computed using a mixed design model analysis of variance (ANOVA) whereas reduction of ASD symptoms over time in both groups with respect to the scores on CARS-2 and CASD was calculated using the paired samples t-test (Pallant, 2013).

4.4.11. Experimental procedures- Pilot and feasibility Randomized control trial (RCT)

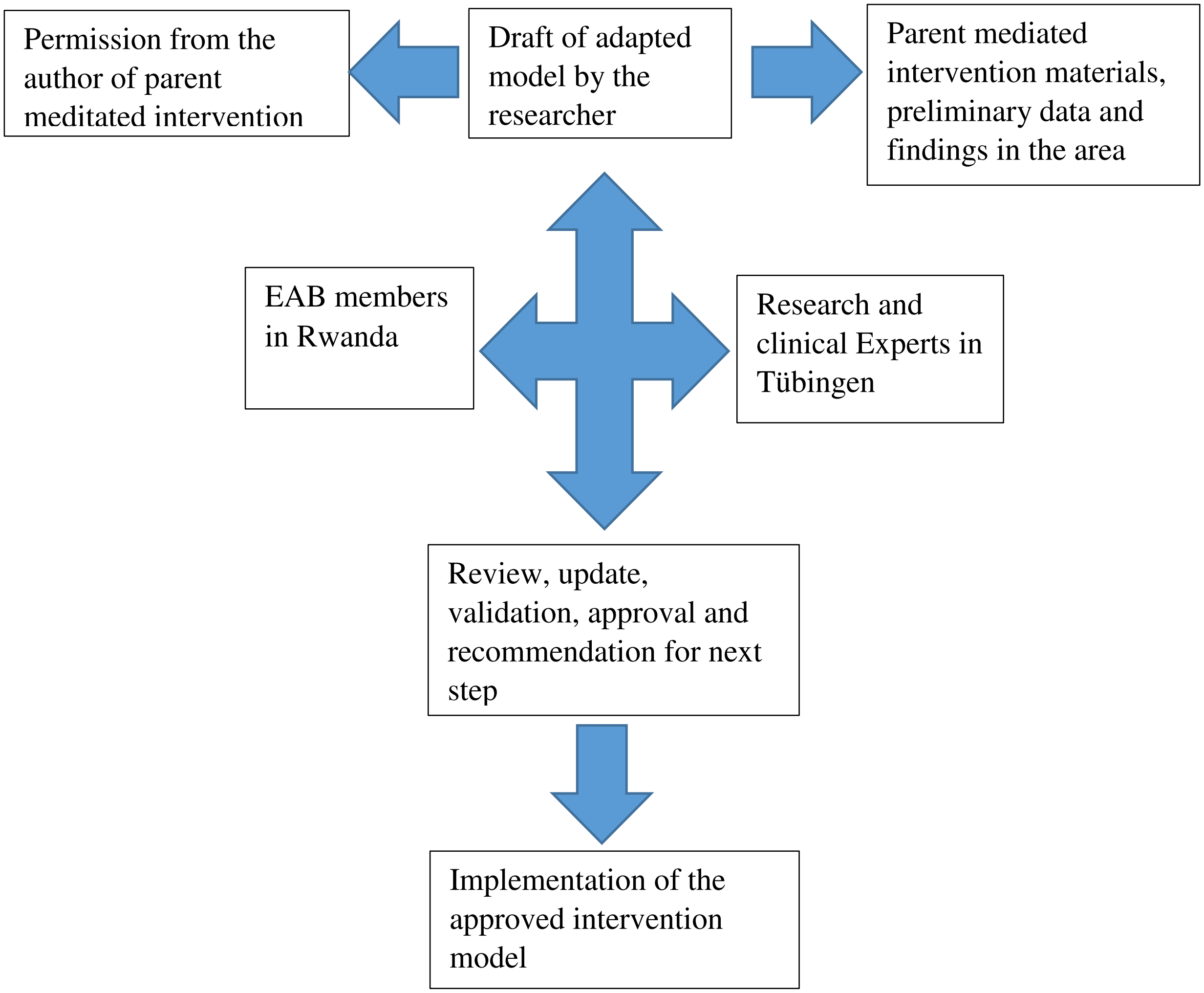
4.4.11.1. Background of the existing evidence-based intervention

The Parent mediated intervention for ASD is a family therapy in nature, developed based on components and the concept of Naturalistic Developmental Behavioral Interventions (NDBIs) or conceptual foundation of key deficiencies in autism (Schreibman et al., 2015). Parents of children ASD were to participate in training sessions that included joint attention, verbal and physical imitation, social engagement, and adaptive skill. Parent mediated intervention was initiated and tested in India Jawaharlal Institute of Postgraduate Medical Education and Research (JIPMER. Intervention included (1) one on one discussion to help parents understand the training principles and reinforcement techniques; (2) practical demonstration of simple activities that can be employed on home-basis and (3) the Implementation of interventions at home on daily basis for 2-hours duration, for twelve weeks (Manohar et al., 2019)

Adaptation of parent mediated intervention for ASD developed in India

The process of adaptation started by obtaining permission from the author to adapt the parent mediated intervention. Researcher developed a draft of adapted model (Family focused training therapeutic approach about ASD in sub- Sahara Africa). The drafted adapted model was based on parent mediated intervention materials, preliminary data (challenges and coping strategies faced by parents and clinicians caring for the Children with ASD) and research findings in the area of ASD related interventions.

Figure 5: The process of adaptation of Indian parent mediated intervention



The adaptation consisted of developing an adapted intervention care model (materials and protocols) that was presented to the EAB for revision, updating, validation and approval. Some parts of the existing evidence based intervention (Indian parents mediated intervention for ASD) were altered, other interventions were eliminated, whilst incorporating new interventions. This adaptation conducted by EAB consisted of training manual with training goals, structure and/or protocols of the intervention care model, which contained the number of training sessions, duration, training procedure, and training topics based on Rwandan context, the therapist and her/ his professional background as well.

Prior to its submission to the EAB members, the first draft of the adapted intervention model was discussed extensively during several meetings with the research team clinical experts from Hospital university of Tubingen and PhD supervisors. The consensus on the last version of the adapted model was finally reached and then sent, to the EAB in Rwanda for review and updating. The EAB was comprised of research and clinical experts, lecturers, stakeholders and parents' representative. The researcher opted for participatory planning methods to ensure that local expertise and experiences were reflected in the diagnostic and intervention care model. Thus, the emphasis was the engagement of key stakeholders. Fifteen (15) individuals, comprising parent representative, staff from non-profit organizations, high-level representative from Ministry of Health, a psychiatrist, a psychologist and representative of health centers, representative of district hospitals and referral hospitals and lecturer from University of Rwanda and the directors of special needs schools were involved in the EAB approval. The adapted model was approved by all the EAB members and recommended for the next step which was the implementation stage. The process of adaptation took 5 months approximately, January to May 2021 and was followed by the implementation phase. The table below includes all adaptations conducted on the parent-mediated intervention as developed in India (Manohar et al., 2019).

Table 11:*Comparison between the original intervention care model and the proposed adapted intervention care model*

Elements of adaptation	**Original model (Parent Mediated intervention)**	**Adapted model (FASSA)**	**Reason for adaptation**
Practice setting	Child Guidance Clinic (CGC) of a non-funded tertiary care hospital in India	Training for family members at Home/ family in Rwanda	Accessibility and high level stigma and financial problems
Target population	Children of 2-9 old years but the severity of ASD not specified	Children of 4-12 years with moderate and severe ASD	Older children due to the delay of ASD identification and diagnosis
Severity of ASD	Not clarified	Children with moderate and severe ASD	Children with simple ASD cannot be exposed to the same interventions
Participants	Parents	Parents, ASD child, siblings, other important person living in family and chief/ representative of the extended family participating in the same training sessions	All family members living with ASD child should take responsibility to care for the child to reduce parent caring burden
Therapists	Parents	Principal investigator & Parents	At the end of each training session, the family continued exercise for two weeks before the next training session
Principles	Naturalistic Developmental Behavioral Interventions (NDBIs)	NDBIs & Family based approach	Developmental behavioral interventions are conducted in family context

Table 14: *Comparison between the original intervention care model and the proposed adapted intervention care model (continued)*

Elements of adaptation	Original model (Parent Mediated intervention)	Adapted model (FASSA)	Reason for adaptation
Interventions	Parent training Parent mediation by exercising the new skills to the ASD child	Family focused training Parent mediation by exercising the new skill to the ASD and other family member as well	To involve all family members at the same time
Training themes	Joint attention Imitation Social skills Adaptive skills	Psycho-education Joint attention Imitation Social skills and Adaptive skills	Psycho-education is important component to be incorporated as parents and family members are short of knowledge in regards of ASD
Duration of the model and number of sessions	A monthly training session 3 months 3 sessions with parents Total of 3 months	A two weekly training session 3 months 5 sessions with family members Total of 6 months	Introductory session is very important to initiate therapist-family relationship. Termination session is needed for closing the therapist-family relationship
Treatment outcomes	Parent stress coping & improvement of severity	Intervention feasibility Improvement of the severity of ASD symptoms	The target is the ASD child not parents
After intervention follow up	Family doctor	Health center, district hospital, referral hospital or NGOs operating in Rwanda	In Rwandan context, the family Doctor is not common and does not exist for all. Communities are closed to HC and DH which provide mental health services.

Note. The original intervention care model - Parent Mediated intervention- India; and the proposed adapted intervention care model - Family Focused Training intervention for ASD among children in sub-Sahara Africa- Rwanda

4.4.11.2. Protocol for the study

Like parent mediated intervention, the study adapted intervention care model, Family-focused training intervention care model for ASD in sub-Sahara Africa (FASSA) whereby the psycho-education, joint attention, imitation, social skills and adaptive skills were the focus for intervention. Different from training sessions conducted for children in specialized health care settings, FASSA consisted of training sessions conducted in the family- home setting involving all family members, the ASD child and the therapist. The family members included parents, the child or adolescent with ASD, siblings, a girl or woman servant, or any other person living with the family. However, African culture in general and Rwandan culture specifically, recognizes the influence of the chief of the extended family in making decision and solving problems in family matters. This study intervention, therefore, considered the influence of the chief in African and Rwandan families and involved them in different training sessions for acceptability purposes.

This study was a manual based training that was adapted basing on parent mediated intervention treatment manual and principles, preliminary research findings of challenges and coping strategies of parents and clinicians caring Children with ASD as well as the research findings in the area of ASD related intervention.

The training manual consisted of five structured sessions which were conducted by the therapist (PhD candidate) in family/ home where the ASD child lived. These one-to-one sessions lasting 90 minutes each, were conducted on two weeks' intervals over a period of 3 months. Sessions were led by the PI, but participants at times selected one of the family members to be a rapporteur. Each session proceeded as follows: (1) Welcoming participants and introduction; (2) Goals of the session; (3) Review of the previous session and report, a review of previous week's list of problems (client and family experience since last session that include relevant events of the previous week, homework feedback and the client current emotional status); (4) Presentation, discussion of the new theme and role-play; (4) Homework for the upcoming weeks and questions and (5) Closing.

For successful training sessions, the therapist used training based skills that were role-plays and/or simulations, demonstration and specific examples. The role-plays and/ or simulations offered specific examples, reflected the real life and routines in the context of the family of interest. All participants were requested to be involved in role-plays and homework at the same level so that the ASD child could have a good opportunity to imitate other family members.

Through training sessions, both the Children with ASD and family members conceptualized how to characterize and recognize negative feelings, associated emotions, and children's reactions/responses. Moreover, they also learnt how reactions associated with the child's emotions could negatively impact the social communication and behavior of the ASD child. Participants acquired strategies that could assist them, especially the ASD child who learnt how to cope with negative feelings/ emotions. In return, this improved ASD symptoms, specifically, symptoms affecting social skills and adaptive behaviors. The table 16 displays a summary of training sessions, topics and training goals. While the scripts for each training session, topics and activities are found on appendix 7.1.

Table 12:*Summary of intervention training sessions, topics and goals*

Sessions	Topics	Goals
Initial phase: Rapport, relationship and goals		
Meeting with family	Introduction	This will be an opportunity for participants and the clinician for: o Building trust relationship o Discussing goals of the intervention o Making contract/ commitment o Agreeing on training sessions structure, venue, agenda and time schedule
Working phase: Training sessions		
Session 1	Psycho-education	Participants will learn ASD symptoms& maladaptive behaviour and how to cope with such behaviour.
Session 2	Joint attention training	Participants will learn how to engage the ASD child for joint attention. All family members will be involved in activities that allow joint attention with children. Role-play will help the participants to understand. It is suggested that peer training by siblings is a good opportunity to develop social skills for the ASD child. Homework will be provided and be reported in next training session. Parents will coordinate the same exercise every day during the two next following weeks before the next session.

Table 13: *Summary of intervention training sessions, topics and goals (continued)*

Sessions	Topics	Goals
Session 3	Imitation training	Participants will learn how to engage the child in routine activities by modelling. Children learn by imitating older persons. Role play will be conducted and homework given to be reported during next training session. Parents will coordinate the same exercise every day during the two next following weeks before the next session.
Session 4	Social skills training	Participants will learn how to engage a child in social interactions. Some activities will be performed all together for the social engagement. Role-play will be performed and homework will be provided and be reported in following training session. Parents will coordinate the same exercise every day during the two next following weeks before the next session.
Session 5	Adaptation skills	Participants will learn to perform independent hygiene. Some activities will be performed all together. Role play will be used and homework to be performed during the following week will be assigned to the participants. Parents will coordinate the same exercise every day during the two next following weeks before the next session.
Termination phase		
Family meeting	Summary of all sessions Continuous contact telephonically with the health centre Appointments monthly to the health centre Homework	Participants make a summary of all specific skills learned throughout all sessions and make observations on how were improved the family dynamism. Homework will be provided and be reported in the following training session
	End of treatment and way forward	Closing and give mutual feedback on the intervention conducted in family

4.4.12. Data management and ethical considerations

Data management and ethical considerations are part of the section on methods and materials of the study assessment of ASD symptoms in family context in Rwanda (chapter 2).

4.5. Results

4.5.1. Description of participants at baseline assessment

The table below displays characteristics of children with ASD at the baseline assessment

Table 13: *Baseline demographics of children with ASD*

		Intervention group			Control group			
	Variables	Frequency		%	Frequency		%	
Age	4-6 years	6		30%	5		24%	76%
	7-12 years	14		70%	16			
	Mean ±SD	7.65 ± 2.33			7.42 ± 2.11			
Gender	Female	2		11%	3	18	17%	83%
	Male	18		89%				
School	Enrolled	9		45%	9	12	43%	57%
	Not enrolled	11		55%				
Community	Rural	10		50%	6	15	27 %	
	Urban	10		50%			63%	
Category of ASD	Moderate	1	19	5%	6	15	29%	71%
	Severe			95%				

Study participants were recruited after a diagnostic procedure that was aimed at confirming the children with an ASD diagnosis. The recruitment was conducted from June 2021 to July 2021, in Kigali city and in closer districts (less than 1 hour travelling) to Kigali City. The sample size was 41 participants; thus of 86 participants (children with confirmed ASD in the study 1), 21 were randomly enrolled in FASSA intervention group and 21 enrolled in the control group (which continued on the usual treatment). As displayed in the table 17, the majority of participants were school age children with 70% (*n*=14) in intervention group and 76% (*n*=16) in control group; while the minority was preschool age 30% (*n*=6) for intervention group and 24% (*n*=5) from the control group. Male participants were 89 % (*n*=18) and 83% (*n*=18) for intervention group, while female participants were 11%, (*n*=2) and 17% (*n*=3) subsequently. In addition, findings revealed that a half of participants for intervention group (50%, *n*=10) live in Kigali city and in rural areas; while the majority of participants (63%; *n*=15) for control group live in Kigali City and 27% (*n*=6) stay in rural area. Furthermore, the current study revealed that majority of participants with 55% (*n*=11) were not enrolled in school (mainstream schools or special schools) for intervention group and 57% (*n*=12) for control group, while their chronological age permitted them to be enrolled in school. More than a third of Children with ASD 45% (*n*=9) in intervention group were not enrolled in schools for the intervention group versus 43% (n=9) who were not enrolled (the control group). Lastly, most participants were children with severe ASD (95%, *n*=19) in intervention group and 71% (*n*=15) in control group versus 5% (*n*=1) of children with moderate ASD for intervention group and 29% (*n*=6) children with moderate ASD in control group.

Regarding mothers' socio-demographic variables, results from the present study displayed that the majority of mothers were between the ages 34-48 years (65%; n=13) for the intervention and the range between 49-64 years old was less represented (5%, *n*=1) in the intervention group. Primary education (50%; *n*=10) in intervention group and 38% (*n*=8) in control group, was common amongst the participants in both intervention group and control group; while only three mothers were subjected to any form of education (7.1%, *n*=3). The university education was common among the study participants with 35% (*n*=7) in intervention group and 38% (*n*=8) in control group. Lastly, the majority (70%; *n*=14) of participants were socioeconomic status category 3 (ubudehe category 3) for intervention group versus 72% (*n*=15) for control group. The socioeconomic status category 2 (ubudehe category 2) was represented by 20% (*n*=3) for intervention group versus 14% (*n*=4) for control group while the socioeconomic status category 4 (ubudehe category 4) was not represented (0%; *n*=0). The table below, displays the socio-demographics of the mother who have autistic children participating in the present research.

Table 14: *Baseline demographics of the mother of children with ASD*

		Intervention group		Control group	
	Variables	Frequency	%	Frequency	%
Mother age	19-33 years	6	30%	8	38.1%
	34-48 years	13	65%	11	52.4%
	49-64 years	1	5%	2	9.5%
	Mean ± SD	36.55 ± 6.27		37.57 ± 8.50	
Mother education	None	3	15%	0	0%
	Primary	10	50%	8	38%
	Secondary	0	0%	5	26%
	University	7	35%	8	38%
Mother occupation	Public servant	2	10%	5	24%
	Agriculture	4	20%	4	19%
	Self-employment	9	45%	4	19%
	No job	5	25%	8	38%
Socioeconomic status (Ubudehe category)	1	2	10%	3	14%
	2	4	20%	3	14%
	3	14	70%	15	72%
	4	0	0%	0	0%

4.5.2. Other services used along with the study intervention (TAU)

Findings from the present study uncovered that more than a half (56.1%; *n*=41) of participants did not receive any alternative treatment programs to manage autistic children (intervention group (50%, *n*=10) and control group (61.9%, *n*=13). Almost a third (29.3%, *n*=12) of the participants were enrolled in special schools (intervention group (30%; *n*=6; 18hours/ week) and control group (28.6%, *n*=6; 18 hours/ week)). Only three participants (7.3%; *n*=3) were enrolled in mainstream schools (intervention group (5%; *n*=1; 30 hours/ week) and control group (9.5%, *n*=2; 30 hours/ week)).

Three participants (7.3%; *n*=3) were under medical treatments (intervention group (15%; *n*=3) and control group (0.0%, *n*=0)). These children with ASD were under treatment for comorbid diseases and/ or symptoms requiring medication. The current study revealed that none (0.0%, *n*=0) of participants was receiving paramedical intervention for both intervention group and control group. The paramedical interventions include speech therapy or and physiotherapeutic services. However, there are no specific services offered to autistic children in both ordinary schools or special schools.

Table 15: *Comparison of intervention and control groups with regards of TAU*

	Medication	Special school	Mainstream school	None	Paramedical intervention	Total
Intervention group	3 (15%)	6 (30%)	1(5%)	10 (50%)	0 (0.0%)	20 (100%)
Control group	0 (0.0%)	6 (28.6%)	2 (9.5%)	13 (61.9%)	0 (0.0%)	21 (100%)
Total	3 (7.3%)	12 (29.3%)	3 (7.3%)	23 (56.1)	0 (0.0%)	41 (100%)

4.5.3. Feasibility for the study

In present study, the feasibility was operationalized through the recruitment of participants, retention or attrition and acceptability (attendance and satisfaction) as well. In the intervention group, parents evaluated the quality of training sessions by SRS and CORS at termination of each meeting.

4.5.3.1. Attendance rate and total hours of intervention

Findings from the current study, revealed that the retention rate was twenty families out of 21 families (97.3%; *n*=42) versus only one family that withdrew from the study during the follow up time making a total of 2.38% (*n*=1) for attrition rate. With reference to the attendance of family members during the training sessions, the majority (seventeen families (85%; *n*=17) of participant families had families' members who were present throughout the 5 training sessions with attendance rate of 100%, while three (15%, *n*=3) families had some family members who were absent through-out the 5 training sessions, with the attendance rate of (85.7%, 90% and 97%) respectively. Thus, the overall training sessions attendance rate of family members was 98.5%.

Furthermore, training sessions by therapist (PI) were conducted in planned hours 100% (2hrs/ session x 5 sessions= 10hrs) and all intervention sessions topics were completely covered with all participating families (100%). Lastly, findings showed that the training hours spent by parents or family members were 11 hours per week/ 14 hours per week (95.7%). High retention rates, families 'members' attendance rates during training sessions, success and high level of participation in training sessions and involvement of families 'members in daily training, indicates acceptability and feasibility of the FASSA intervention in families.

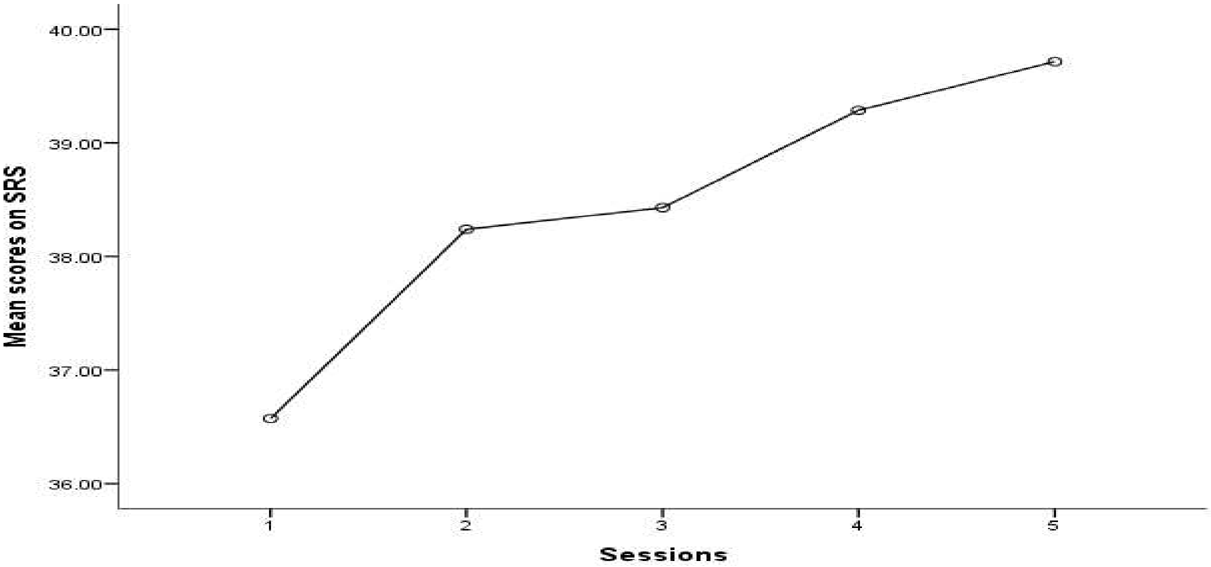
4.5.3.2. Description of scores achieved on SRS and CORS

The feasibility of the intervention was measured throughout the treatment alliance measures. In the present study the treatment alliance measures included SRS and CORS. The one way repeated measures ANOVA was employed to analyze data for therapeutic alliance measures. The SRS and CORS scores were obtained by summing the marks made by the parent who placed a mark on nearest centimeter of each of the four lines. The line was estimated to have 10 cm and parent was placing mark corresponding to the score in terms of the training session (SRS) or the child outcomes after training sessions (CORS). For SRS the possible total score is 40, while a score below 36 is a subject of concern to which the client should comment. For CORS, the total possible score is 40, or 10 on any score. The cut- off for CORS (for children) is 28 out of 40 total score; while the cut-off scores for the SRS is 36 out of 40 total score. It was expected to find increases in scores achieved on SRS and CORS throughout the different training sessions (from session 1 to session 5)

One-way repeated measures ANOVA was performed for comparing the mean score achieved on SRS and CORS as rated by parent at: session 1(*psychoeducation*), session 2 (*joint attention*), session 3 (*imitation*), session 4 (*social skills*) and session 5 (*adaptive skills*). The table 16 displays the mean or standard deviations reflecting the increases. The test showed a significant effect for time, Wilks' Lambda = 14, *F* (4.17) = 25.73, *p*= <.05, multivariate partial eta squared=

.86. The significance level was .05 while the effect size is represented by the partial eta squared. These findings indicate that increases in time (number of session) resulted in increase in score on the SRS. The figure 6 showed clearly increases of the scores achieved on the SRS throughout five training sessions.

Figure 6: Satisfaction of parents with regard to training sessions (SRS)



As displayed in table 20, these findings were confirmed by measures of central tendency showing increases in scores achieved on SRS; session1 (*M*=36.57; *SD*=1.02; *Min*=34 and *Max*=38), session2 (*M*=38.23; *SD*=1.67; *Min*=35 and *Max*=40), session3 (*M*=38.42; *SD*=1.39; *Min*=36 and *Max*=40), session4 (*M*=39.21; M=40; *SD*=1.18; Min=37 and *Max*=40) and session5 (*M*=39.71; *SD*=.95, *Min*=36 and *Max*=40) respectively.

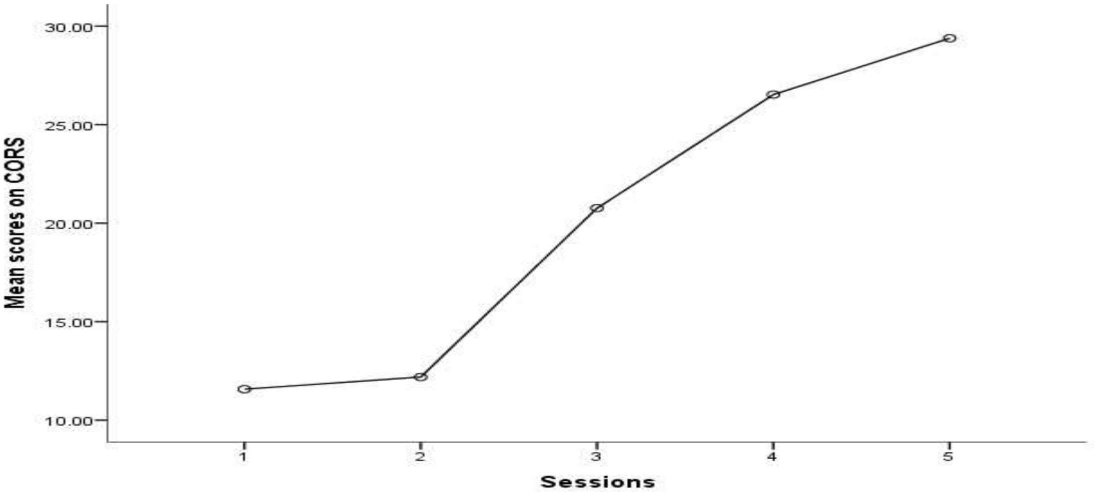
Table 16: *Descriptive statistics of the session ratings (SRS)*

Sessions	*M*	*Md*	*SD*	*Min*	*Max*
Session 1	36.57	37.00	1.02	34.00	38.00
Session 2	38.23	38.00	1.67	35.00	40.00
Session 3	38.42	38.00	1.39	36.00	40.00
Session 4	39.21	40.00	1.18	37.00	40.00
Session 5	39.71	40.00	.95	36.00	40.00

Note. *M* = mean; *Md*= median; *SD*= standard deviation; *Min*=Minimum and *Max*= Maximum

The figure 7 displayed, an increase in the scores achieved on the CORS from training session one (1) to training session five (5). Besides, one-way repeated measures ANOVA was conducted comparing score by parent child outcome rating at session 1(*psychoeducation*), session2 (*joint attention*), session 3 (*imitation*), session 4 (*social skills*) and session 5 (*adaptive skills*). The table 17 displays the mean and standard deviations suggesting increases.

Figure 7: FASSA outcomes as measured using CORS



In the present study, a significant effect for time was found, Wilks' Lambda = .066, *F* (4.17) = 60.01, *p*= <.0005, multivariate partial eta squared= .96. The significance level was .05

while effect size is represented by partial eta squared. This finding indicates that increases in time (number of session) resulted in increase in scores on the child outcome rating scale ,which is corroborated by the descriptive statistics (measures of central tendency) showing increases in scores achieved on CORS; session 1 (*M*=11.57; *SD*= 4.01, *Min*=5 and *Max*=18), session 2 (*M*=12.19; *SD*=4.45, *Min*=7 and *Max*=19), session 3 (*M*=20.76; *SD*=5.42, *Min*=9 and *Max*=30), session 4 (*M*=26.52; *SD*=5.32, *Min*=16 and *Max*=34) and session 5 (*M*=29.38; Md=32; *SD*=5.32, *Min*=17 and *Max*=36) respectively.

Table 17: *Descriptive statistics of the children outcomes (CORS)*

Sessions	*M*	*Md*	*SD*	*Min.*	*Max.*
Session 1	11.57	11.00	4.01959	5.00	18.00
Session 2	12.19	12.00	4.45987	7.00	19.00
Session 3	20.76	21.00	5.42130	9.00	30.00
Session 4	26.52	28.00	5.32559	16.00	34.00
Session 5	29.38	32.00	6.11945	17.00	36.00

Note. *M* = mean; *Md*= median; *SD*= standard deviation; *Min*=Minimum and *Max*= Maximum

In sum, findings from the present study confirm that the set of hypotheses concerning the therapeutic alliance and reduction in symptoms. In line with hypothesis 1 and 2 (page, 93), compliance with FASSA interventions was revealed in families of children with ASD, evidenced by parent’s expressions of satisfaction pertaining the training sessions and the positive progress of children’s behavior as measured by the SRS and CORS. The parents did not report any negative experiences that could have resulted in the therapist changing the training approach or style.

4.5.4. Reduction of ASD symptoms

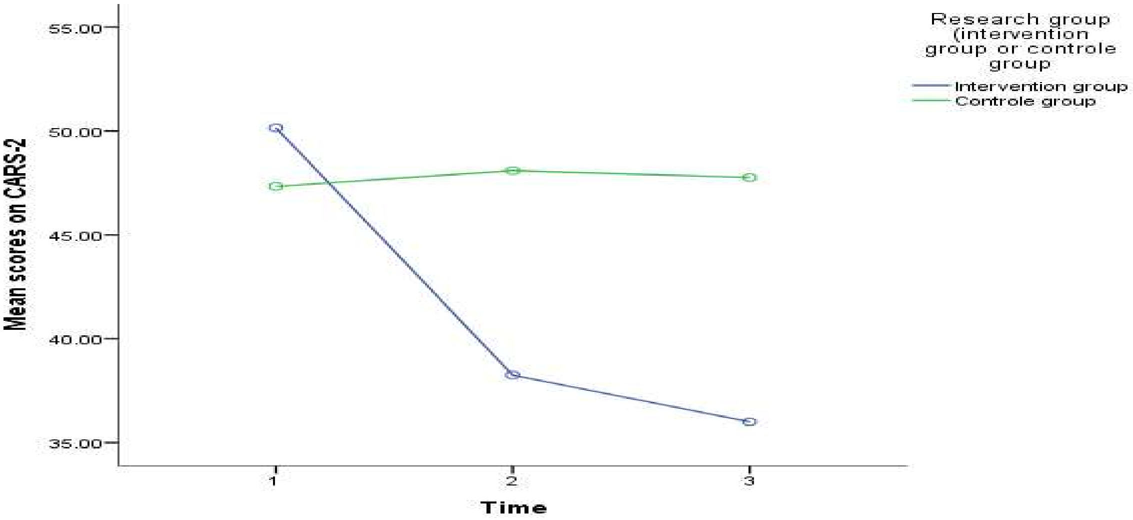
To investigate the ASD symptoms changes, the children ASD symptoms were measured using the CARS-2 and the CASD and a mixed design model analysis of variance (ANOVA) suggesting a reduction in core autism symptoms observed on both the CARS-2 (*F* (2,38): 26.37, *p*=<.05) and checklist for autism spectrum disorder (*F* (1,39): 12.12, *p*=<.05) total scores.

4.5.4.1. Reduction of ASD symptoms on CARS-2 scores from baseline to 24 weeks

Mixed design model analysis of variance (ANOVA) was performed for assessing the effect of interventions (FASSA + TAU and TAU only) on participants' scores on CARS-2, across three time periods (pre-treatment assessment, end therapy assessment and follow up assessment). Significant interaction was found between two groups (intervention group and TAU group/ control group) and time, Wilks' Lambda=.48, *F* (2.38) = 20.47, *p*<.05, partial eta squared=.52.

There was a main effect for time, Wilks Lambda = .42, *F* (2.38) = 26.40, *p* < .05, partial eta squared=.58, with both groups suggesting reduction in ASD symptoms across the three periods of assessment in intervention group while the control group did not have change over time. The figure 6 shows reduction of symptoms as measured by CARS-2 among children with ASD assigned to intervention group with TAU and those who were assigned to control group with TAU

Figure 8: Reduction of ASD symptoms on CARS-2 scores from baseline to 24 weeks



The main effect for time was significant. Main effect comparing the two types of intervention was significant, *F* (1.39) = 8.70, *p* < .05, partial eta squared=182, suggesting difference in the effectiveness of the two interventions and a very large effect size. Here, the effect size intervention was reflected through the partial eta squared.

Table 18: *CARS-2 statistics scores for intervention group (FASSA with TAU) and control group (TAU only)*

	Intervention			Treatment as usual		
Time periods	*N*	*M*	*SD*	*n*	*M*	*SD*
Pre-treatment assessment	20	50.15	7.07	21	47.33	6.38
End therapy assessment	20	38.25	8.66	21	48.09	5.97
12 weeks follow up assessment	20	36.00	10.69	21	47.76	7.07

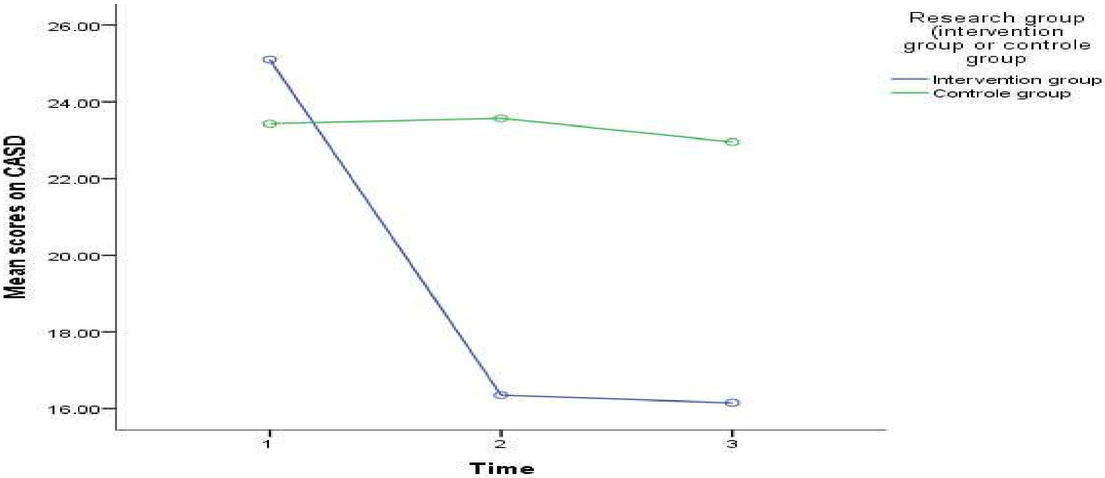
Note. *M* = mean and *SD*= standard deviation

The effectiveness is substantiated by the central tendency measures as displayed in the table 24, intervention group (*M*=50.15; *SD*= 7.07 for pretreatment assessment; *M*=38.25, *SD*= 8.66 for end therapy assessment and *M*=36.00, *SD*= 10.69 for follow up assessment) and control group (*M*=47.33; *SD*= 6.38 for pretreatment assessment; *M*=48.09; *SD*= 5.97 for end therapy assessment and *M*=47.76; *SD*= 7.07 for follow up assessment).

4.5.4.2. Reduction of ASD symptoms on CASD scores from baseline assessment to follow up assessment weeks

Mixed design model ANOVA was carried out for evaluating effect of interventions (FASSA + TAU and TAU only) for participants' scores achieved on the CASD, over three time periods (pre-treatment assessment, end therapy assessment and follow up evaluation). Results showed significant interaction between two groups (intervention group and control group) and time, Wilks' Lambda=.42, *F* (1,39) = 23.98, $p < .05$, partial eta squared=.56. There was a main effect for time, Wilks Lambda = 46, *F* (1.39) = 22.54, $p < .05$, partial eta squared=.54, with both groups showing a reduction in ASD symptoms scores across the three periods. Comparing two types of intervention, the main effect was significant, *F* (1.39) = 12.12, $p < .05$, partial eta squared=.237, that suggests a difference in the effectiveness of the two interventions as measured by CASD with large effect size and the intervention effect size

Figure 9: *Reduction of ASD symptoms on CASD scores from baseline to 24 weeks*



This is confirmed by the central tendency measures as displayed in the table 24, intervention group (*M*=25.10; *SD*= 2.90 for pretreatment assessment; *M*=16.35, *SD*= 6.43 for end therapy assessment and *M*=16.15, *SD*= 6.49 for follow up assessment) and control group (*M*=23.42; *SD*= 2.99 for pretreatment assessment; *M*=23.57; *SD*= 3.17 for end therapy assessment and *M*=22.95; *SD*= 3.70 for follow up assessment).

Table 19: *CASD of statistics test scores for intervention group (FASSA with TAU) and control group (TAU only) across three time periods*

	Intervention			Treatment as usual		
Time periods	*n*	*M*	*SD*	*N*	*M*	*SD*
Pre-treatment assessment	20	25.10	2.90	21	23.42	2.99
End therapy assessment	20	16.35	6.43	21	23.57	3.17
12 weeks follow up	20	16.15	6.49	21	22.95	3.70

Note. *M* = mean; and *SD*= standard deviation

Also, a paired-samples t-test was performed to assess how the intervention affected the children with ASD's scores on CARS-2 and CASD. A statistically significant decrease was found in CARS-2 score from baseline (*M*=50.15, *SD*=7.07) to end therapy (*M*=38.25, *SD*=8.66), *t* (19) =6.89, *p*<.0005 (two-tailed). Mean decrease in CARS-2 scores was 11.90 (95% confidence interval that ranges from 8.28 to 15.51). Eta squared statistic (.70) indicating large effect size. Furthermore, statistically, significant decrease was found on CASD score between baseline assessment (*M*=25.10, *SD*=2.90), end therapy assessment (*M*=16.35, *SD*=6.43), *t* (19) =6.43, *p*<.0005 (two-tailed). Mean decrease on CASD score was 8.75 (95% confidence interval ranging from 5.90 to 11.59). The eta squared statistic (.68) indicated large effect size. Paired-samples t-test revealed statistical significant decrease in CARS-2 scores from end therapy (*M*=38.25, *SD*=8.66) to follow up (*M*=36.00, *SD*=10.69), *t* (19) =1.48, *p*<.0005 (two-tailed). The mean decrease in CARS-2 scores was 2.25 with a 95% confidence interval ranging from -.92 to 5.42. The eta-squared statistic (.10) indicated very large effect size. However, the results demonstrated no statistical significant decrease on CASD score end therapy assessment (*M*=16.35, *SD*=1.43) and follow up assessment (*M*=16.15, *SD*=1.45), *t* (19) =.18, *p* >.0005 (two-tailed). A mean decrease on CASD score was .20 (95% confidence interval ranging from -2.10 to 2.50).
For *control group with TAU*, the paired-samples t-test revealed no statistically significant differences in mean between baseline and end therapy assessments (CARS-2, *p*=.062; CASD, p=.766).; between end therapy and follow up assessments (CARS-2, *p*=.674; CASD, *p*=.255).and between baseline and follow up treatment (CARS-2, *p*=.668; CASD, *p*=.421).

The findings confirming the hypotheses (hypotheses 4 and 5) stating that FASSA is useful in the reduction of the severity of ASD symptoms, is apparent in the children allocated to the intervention group as compared to children allocated to the control group. For the intervention group, the symptoms were less severe at end therapy and follow up assessments, from baseline assessment as compared to the control group whose symptoms remained unchanged throughout all of assessments.

4.6. Discussion

4.6.1. Feasibility of the study

For the first time, a RCT of the FASSA was done in Africa, specifically in Rwandan context. The present study involved forty-two (*n=42*) families having children with ASD including families randomized to receive the intervention (*n* = 21) with TAU and families randomized for control group and TAU (21). The retention or attrition, adherence or alliance satisfaction were considered as feasibility outcomes. Feasibility outcomes indicated that the FASSA is a feasible and acceptable intervention for families of children with ASD in Rwandan context. FASSA was effective, interesting, well received by parents and family members in general, and was highly attended by family members. The program was delivered as it was expected.

The researcher adopted a feasibility study instead of evaluation study due to limited time, financial resources and stigma that led to a very small sample while evaluation study required larger samples (Hooper, 2019). In addition, it was the first time for FASSA to be implemented in the Rwandan context. Thus a pilot and feasibility trial was necessary to determine information on feasibility of intervention delivery, intervention acceptability, recruitment, sampling and randomization, assessments, as well as end therapy and follow up that aided in informing the researcher to design a more decisive and adequate randomized clinical trial. The pilot and feasibility study were chosen as it allowed the researcher to test whether the major components of the intervention could work successfully. The data from the pilot and feasibility trial was expected to inform the sample sizes for next steps of trial for extensive RCTs.

4.6.1.1. Attrition rate, recruitment rate, attendance rate, fidelity and acceptability

The attrition rate of 2.38% and forty-two out of forty-four (95%, *n=44*) families who were approached and available, were recruited and signed consent for participating in this research. Thus, the accrual rates (recruitment and retention rates) informs future definitive trial design. One hundred percent (100%) sessions training were successfully conducted in families and for eighty-five percent of families, family members attended 100% training sessions of the FASSA. While the overall training sessions attendance rate for family members was 98.5%, families were very interested in and grateful for the intervention because there were no other alternative treatments available for their children after receiving an ASD diagnosis. Following the ASD diagnosis parents were told to return home where many challenges including stigma and lack of social support were the order of the day (Papadopoulos, 2021). Thus, any initiatives to help them to find solution to their ASD related problems were significantly welcomed.

Findings from previous studies conducted in home based interventions showed minor differences in results. For example, Rahman and colleagues (2016) revealed that the majority of families (81%) had completed the intervention; while a study conducted by Beaudoin, Sébire and Couture (2019) specified a high attrition rate of 52.3%. In the same vein, Manohar and research team (2019) revealed relative low participants dropout rate (20%) after 3 months of intervention with 94% having attended between 4 to 5 training sessions; and 86% having attended all expected training sessions (5 sessions).

For the present study, excellent fidelity was evident and was reported and monitored in home logbook. All components of the intervention were completely delivered up to 100% (n=21) during the training conducted by the therapist and by family members, during training to the extended follow up period. Pertaining fidelity, findings were consistent with results from another home based study implying a high therapy fidelity, as components of the intervention monitored on the check list were totally delivered up to 92 % (Manohar et al., 2019).

The present study was conducted with average intensity of 11 hours per week, and the training sessions conducted by one family member, ranged between 6 hours to 14 hours per week for 24 weeks. The training sessions conducted by the therapist for family members were equivalent to 2 hours per 2 weeks for twelve weeks. These findings are almost similar to the current literature. A home based parent training program conducted by Ho (2020) estimated the average of intensity of training at 10.1 hours a week for intervention group and 9.0 hours for control group whereas a study conducted by Juneja (2012) estimated an average of training hours at the range of 5.25 hours to 10.5 hours a week for parents. In addition, a study conducted by Manohar (2019) revealed that the average of training hours was 8.37 hrs per week.

Another study, with different results, training parents of preschool children with autism, involved higher training intensity with average of 15.2 hours per week (Deb, Retzer, Roy, Acharya, Limbu & Roy, 2020; Pajareya & Nopmaneejumruslers, 2011). Studies conducted to investigate the contribution of intervention intensity revealed significant relationship. For example, and Linstead and colleagues (2017) found monthly treatment hours for each domain of intervention (language skills, motor skills, play skills, academic performance, adaptive skills, cognitive, executive function skills, social communication skills) ranging between 5.95 hours per month and 24.94 hours per month. According to the above authors, strong relationship between skills acquisition and treatment intensity was demonstrated. However, other studies conducted previously compromised treatment success when intensity of intervention become increased (Reed, Osborne & Corness, 2007; Virués-Ortega, 2010).

4.6.1.2. Treatment working alliance/ Therapeutic alliance (compliance with the treatment)

The purpose of this study, in terms of a working alliance, was to determine whether the FASSA is practical and acceptable in the context of Rwandan families. To investigate the working alliance measures, SRS and CORS were rated by parents to autistic children after each training session. Findings determined that th

e therapy working alliance ameliorated throughout training session with consolation, knowledge and skills as reported and rated by parents.

These results are in line with earlier studies that looked into the relationship between alliance measures and clinical outcomes. (Campbell & Hemsley, 2009). Other findings revealed that therapy alliance and emotion have impact on outcome of the therapeutic intervention leading to a predictable improvement in functioning (Fisher, Slonim, Bar-Kalifa & Rafaeli, 2016). The other study proposed surveillance and regular updates on the working alliance in order to assist therapists in improving treatment outcomes (Albaum et al. Albaum, Tablon, Roudbarani & Weiss, 2020).

4.6.2. Reduction in ASD of ASD symptoms from baseline to 24 weeks

To researchers' knowledge, this study is the first in Africa generally, precisely in Rwanda, as it investigated the feasibility and acceptability of intervention aimed at reducing ASD symptoms, and conducted in family settings involving all family members. This intervention was conducted in consideration of Rwandan cultural context of family interaction and the manner in which they solve behavioral concerns of children. Thus, the intervention involved all family members or any other important person who lived with the family or a chief of the extended family where applicable. The exploratory analysis of effectiveness revealed large effect sizes for the intervention group, concerning the decline in severity of ASD symptoms over the course of intervention. The results are promising and they suggest that further testing for effectiveness would be worth exploring for a huge sample size. The large effect size noted in the present study could be due to the intensity of interventions as all family members (patents, siblings or other) participated in the training conducted by the therapist every two weeks (2 hours). Moreover, training sessions or exercises continued every day in family setting, by any available family members, (maximum of 2 hours a day during 24 weeks) thus increasing parental care skills and reducing ASD symptoms in turn.

The present study revealed large numerical changes in scores achieved on CARS2, indicating significant improvement on children outcomes and symptoms which could have contributed to motivation and increased parental engagement. Thus, competency may have contributed to symptom reduction in return. Findings are in line with several studies that involved CARS as measure of outcome. For example parents based intervention program among autistic children presented significant improvement in autism symptoms as assessed by CARS (Juneja et al., 2012). A similar study conducted among pre-school children revealed significant greater gains in CARS ($F = 2.1$, $p = .002$). Statistically, significant measure was established between pre intervention and post intervention, in all the measured parameters as reflected on CARS in Sri-Lanka study, due to Home-Based early Intervention for Autism (Perera et al., 2016). Similarly, to this study, a great reduction was obtained in first 3 months of post intervention (Perera et al., 2016). Additionally, other studies adopted early parent training intervention and showed generally reduction in ASD symptom but the outcome measures included ADOS (Kasari et al., 2010; Pickles et al., 2016).

4.7. Conclusion

This research revealed the feasibility and acceptability of FASSA in Rwandan context that assisted family members to gain information about ASD for both symptoms and managing a child with ASD. Furthermore, the current research indicated that FASSA could reduce the ASD symptoms. Educating and empowering parents and other family members about FASSA in early stage of diagnosis, helps to reduce distress within the family, thus boosting the coping skills and increasing competencies in managing a child with ASD. FASSA, which is provided in early stage can aid in addressing problems of delays by instituting interventions and preparing families for more alternative treatment/ interventions. Therefore, FASSA bridges treatment gaps in health care system between specialist interventions (professional as consultant) and non-specialist interventions (parent or family members as therapists). Once effectiveness has been established, FASSA has the potential to provide families and caregivers of children with ASD with a therapy option that is easily accessible, implementable and can address a critical clinical concern.

4.8. Limitations

The present study had several limitations; Firstly, independent assessors relied on parent-report for measuring the outcomes. Thus, parents' or family members' perceptions of the child's behaviors and their routine functions were taken into account. Parent distress, expectations and experiences with health services received from mental health professionals would have influenced information reported. Possibly, stressed parents would express negative responses to the measure of outcomes achieved by the child during intervention. Only parents who could have been biased reported the outcome. In addition, social desirability bias is to be taken into consideration, as truthfulness of responses during the evaluation from parents could have been influenced by reporting symptoms as expected outcomes, because of parents need of positive and favorable perception of their children by others. Thus, for future studies, it is important to involve children and parents' outcomes based on multiple informants such as other community members and siblings or peers. Lastly, the study sample size was relatively small to inform effectiveness of the intervention. Thus, it impossible to generalize the findings. To investigate the effectiveness of the FASSA intervention, a larger, randomized or naturalistic experimental study is needed.

Generally, this research is one of the few, investigating feasibility and efficacy family focused training intervention for ASD, research conducted in home settings. However, no specific effects of the intervention can be ruled out and the observed effects on the children with ASD behavior in relation with the FASSA nonetheless show the probability of successful intervention. This is so because it provides primary information about the feasibility and acceptability of FASSA as delivered in family settings. Furthermore, it is significant to mention that potential negative life events in families were not controlled or evaluated.

CHAPTER V: GENERAL DISCUSSION

5.1. Discussion

Autism is a mentally neurodevelopmental illness effecting child communication skills, behaviors and attitudes that leads to several impairments in language skills, nonverbal communication, social relationship and cognitive as well as adaptive skills which make children with ASD struggle at school and in social life practices (Mojeed, Ani, Lagunju & Omigbodun, 2016; Nguyen, Tran, Pham, Do, Ngo & Nguyen, 2021). This creates immense financial burdens and psychological distress to individuals, families, communities and the country at large (Mojeed et al., 2016). The ASD related deficits and impairments are the starting point in identification of ASD leading to early intervention. Early intervention is the proposed positive impact on ASD outcome, is cost effective and mitigates burden of individuals and families (Penner et. al., 2015; British Psychological Society, 2021). The investigation of the feasibility of FASSA was the overall objective of this dissertation. Therefore, three empirical studies were conducted and results have been summarized within this section.

Chapter II (*study 1*) aimed at re-assessing children with autism in Rwanda. For that reason, a sample of 94 children with ASD was re-evaluated by an experienced psychiatric nurse (Therapist) using two international standardized instruments (CARS-2 and CASD). The analysis revealed no difference between the means scores of children and mothers groups according to their socio-demographic characteristics, achieved on CARS-2 and CASD. Difference between means was only found in condition of birth and mother age at birth of the child and this is consistent with previous studies conducted in that area (Ann et al., 2020; Davidovitch et al., 2020; Robert et. al., 2017). These results indicate that difficult deliveries may cause brain damage which in return contribute in the development of ASD (Cheng et al., 2019). Moreover, current research revealed substantial correlation between CARS-2 and CASD, indicating that they can be used together as measures of ASD in Rwandan context. Findings from the present study suggest that CARS and CASD rests reliable and valid ASD diagnostic instruments when the source of information is client observation together with interaction with the client, parent observation and developmental history as well. The use of CARS and CASD for diagnostic purposes has two advantages (1) they are cost effective (2) due to their brevet, they are time saving and do not require high expertise (Mayes, Calhoun, Mayes, & Molitoris, 2012; Mayes, 2018; Mayes et al., 2009) These instruments all together, were successful of identifying children with ASD and those without ASD; children with LFA and those with HFA. Results from the present study are consistent with previous studies which demonstrated positive correlation and high agreement between CARS and CASD (Mayes, Calhoun, Mayes, & Molitoris, 2012; Mayes et al., 2009).

Chapter III (*study 2*) targeted at identifying the challenges and coping strategies for parents and clinicians caring for children with ASD in Rwanda. Videotaped interviews were conducted on parents and clinicians to gather information about challenges and coping strategies. This met the researcher's expectations of lack of information, financial and caring burden, frustration and stigma as challenges for parents, and clinicians' challenges of minimal knowledge regarding ASD, frustration, overworking and social interaction barriers. Striking and interesting was the same claim from both the nonprofessionals (parents) and professionals (clinicians) on the lack of knowledge about ASD and its care. These predicaments for parents and clinicians hinder the management process for the child with ASD resulting in negative ASD outcomes (Giovanni et al., 2020; WHO, 2013).

Pertaining the coping strategies, parents articulated that self-informing, searching for respite services, reliance on God's power and use of traditional power, acceptance and involvement of the extended family were their coping strategies. On the same vein, clinicians cope with the said obstacles through self-informing means in the same manner the parents do and consult with their colleagues. In harmony with the findings of this research, the other study formulated that peer consultation is carry out by clinicians to gain information, support and advice especially when confused or unknowledgeable (Cloete & Obaigwa, 2019; Sinai-Gavrilov et al., 2019). Moreover, these coping strategies, especially self-informing, are commended in the contribution of successful behavior changes in children and parents (Nefdt et al., 2010).

Chapter IV (*study 3*) investigated the feasibility of FASSA in home based settings. Treatment, adherence and symptoms reduction was observed at the end of training sessions and at termination of the follow up period. The family members were highly compliant with the treatment (FASSA) and as expected, it was to offer them solutions to ASD related problems prevailing within their families. Normally, taking care of the child with ASD, was the mother's responsibility (McCafferty & McCutcheon, 2020; Rankin et al., 2019). However, the treatment granted a good opportunity to the other family members to receive information on ASD and gain skills in caring for the ASD child. Therefore, everyone in the family became responsible and felt that they had a role to play in ASD care.

To measure the reduction of ASD symptoms, the data collected at baseline, both end therapy and follow up was analyzed. The present study witnessed a significant reduction of symptoms in the intervention group than the control group. The reduction of symptoms as measured by CARS-2, revealed a large effect size of .58, as effect for time and moderate effect size of .21, as main effect upon comparing two groups. Then, the reduction of symptoms as measured with CASD, showed a moderate effect size of .54 as effect for time and medium effect size of .17 as main effect upon comparing two groups. This is in line with this study hypothesis stating that FASSA can reduce ASD symptoms. The findings of present research are supported by other studies conducted on home based intervention, pertaining the reduction of ASD symptoms as measured by CARS-2 and CASD (Juneja et al., 2012; Perera et al., 2016; Pickles et al., 2016; Wong & Kwan, 2010).

In summary, the evidence evaluation of the intervention/adaptation of the model was deliberated to answer evaluation questions as follows; (1) was FASSA delivered to the intended population? (families having children with ASD), (2) did the implementation of FASSA follow the protocol? (implemented with fidelity), (3) did families who were assigned to intervention (FASSA) find it helpful and acceptable? (excellent attrition rate, recruitment, retention rate and compliance), (4) did FASSA display potential effectiveness? (reduction of ASD symptoms among children with ASD who were assigned in intervention group than those who were assigned in the control group) (Aschbrenner et al., 2020; Highfield et al., 2015).

5.2. Conclusion

The present dissertation investigated and described ASD symptoms among Rwandan children with ASD. Analysis was conducted on (1) difference between the means of children and mothers' groups based on socio-demographic characteristics, (2) reliability and validity of international standards and (3) correlation between CARS-2 and CASD. Findings from *study 1* revealed no associations between socio-demographic factors of children and mothers, and the ASD symptoms measured via CARS-2 and CASD. The effect of the sociodemographic factors is not clear and could be reflecting multiple confounding factors. Also, the *study 1* demonstrated positive correlation between scores achieved on CARS-2 and scores achieved on CASD which is indicative of an increase in score of CARS-2 resulting in an increase of scores achieved on CASD. Thus, the two international standardized instruments can be used together to diagnose ASD in Rwandan context. The *study 2* revealed lack of information, financial and caring burden, frustration and stigma as challenges faced by parents and minimal knowledge regarding ASD, frustration, overworking and social interaction barriers as challenges faced by clinicians. However, both parents and clinicians developed coping strategies including self-informing, searching for respite services, reliance on God's power and use of traditional power, acceptance and involvement of the extended family for parents and self-informing and consultation with their colleagues.

The analysis of the feasibility of the treatment (*study 3*), displayed high attendance and recruitment rate, good attrition rate, compliance with the treatment, fidelity, acceptability. Also, the present study showed initial efficacy of FASSA and results are promising suggesting a significant reduction of ASD symptoms as evidenced by the large and medium effect size achieved on both CARS-2 and CASD. Therefore, it is recommended that FASSA should be introduced as a model for ASD treatment in health care facilities both private and public. These findings strengthen the relevance of FASSA as an approach for managing ASD in Rwandan context; thus improving the well-being of children with ASD. Furthermore, research participants who were part of control group and other eligible families who missed out on participation study keep requesting for the continuation of this intervention. The high compliance and considerable reduction of ASD symptoms could be due to the fact that the intervention was conducted in home setting that helped to solve problems where they occurred. Furthermore, training sessions involved exercises using routines with which everybody within the family was familiar with.

In the future, further studies may take an interest in evaluating siblings', extended family members', neighbors, political, health and education decision makers' about ASD, as well as cultural or traditional perspectives. The development, adaptation and testing the validity and inter rater reliability (using large samples) of international standardized instruments as algorithms and routines for ASD assessment in Rwandan context; would be a considerable advancement in the process of diagnosis for ASD symptoms. Furthermore, the extension of research population and settings to explore the effectiveness of treatment with large samples are recommended.

5.3. Overall strengths and limitations

As ***strengths***, the research has a powerful ecological validity as it examined the effectiveness for research-based intervention for ASD in family settings (real life settings). Furthermore, it adds on information about the existing literature on ASD interventions in LAMIC settings and for the first time such family interventional study was done in SSA generally and in Rwandan context particularly. To the researcher's knowledge, the present dissertation includes the first study about diagnostic instruments, challenges for caring children with ASD and intervention care model for managing ASD. This offers useful evidence for early detection that lead to early intervention programs, to reduce ASD symptoms and in turn improves the quality of life of children with ASD, reducing parental ASD related stress.

The last strength is related to the outcome of the measurement that was done by independent assessors to assess child primary outcome, and who were unaware of nature of intervention. Current literature stresses inconsistency in terms of effectiveness of intervention for ASD and the difference between parent-rated measure and clinician-rated assessments (Ho & Lin, 2020; Nevill, Lecavalier & Stratis, 2018). For this study the outcome measurement was conducted in collaboration with parents (by symptoms description) and independent assessors (by direct observation of ASD symptoms at home during play with Children with ASD).

This study involved parents to Children with ASD from Kigali city districts and districts closer to Kigali only in Rwanda (which include families in cities and families from remote rural areas). Findings cannot be generalized to other Rwandan districts. At large, the present research is one of the few researches that investigated the feasibility and effectiveness of family focused training performed at home settings. It provided initial information about the feasibility and acceptance of FASSA as delivered in family settings. Therefore, adaptations are required for delivering such interventions in community context. To explore the effectiveness of the intervention (FASSA) a large, randomized or naturalistic experimental interventional research is recommended. Furthermore, the present study is the level of evidence I which involves RCTs considered as the highest level of evidence. Such studies are designed to be unbiased and have less risks of methodical mistakes/ errors. In addition, these studies are said to allow randomization of confounding factors that may bias results (Burns et al., 2015; West et al., 2002).

Regarding ***limitations*** in general the outcome measurements and small sample size are to be considered. Firstly, the measurement of outcome relied on the parent-report. However, the parent's ASD related stress, expectations or experiences with health services, can affect their perception in terms of behavior in child routines, thus leading to negative responses of the outcomes. The outcome was reported by parents who could have been biased. Therefore, it is of great importance for research in the future to include many informants as community members, siblings or peers for measuring child outcomes. Reliability and validity are psychometric properties of a standardized test. However, due to relative small sample size, the present study did not inform the validity and reliability of the international standardized tools for assessing ASD symptoms. Moreover, due to financial constraints, dissemination processes of the findings from the present study, to be availed to the academic researchers, policy makers, government officials, health care providers and the general public are unavailable. Nevertheless, these findings will be published in the searchable data base. A short period interventional program but with long term follow-up is needed.

5.4. Implication for research and practice

Research

As there are no other studies on ASD in Rwanda, the results from the present study will help to enrich and enhance literature on ASD, specifically if it comes to augment knowledge about autism that is growing in Africa. The study is likely to inform further research on ASD matters, particularly in Rwandan context. As home based intervention for ASD are alluded to improve ASD symptoms (Ho & Lin, 2020; Nevill et al., 2018), results from the present research will increase the body of knowledge in the field of ASD.

Practice

The findings from the present study will be disseminated via the report sent to the University of Tübingen (Medical faculty), publication of findings in scientific journals and though conferences and workshops for scientific exchange and sharing. This knowledge informs the policy makers, general public and health professionals on screening ASD among children born with respiratory distress or asphyxia, periodically throughout childhood, given the increased risks of ASD. In addition, the present study revealed a possibility to use international standardized instruments (CARS-2 and CASD) of ASD evaluation in Rwanda for diagnostic purposes. Furthermore, results from the present study will have greater implications for practice as children who participated demonstrated, greater reduction of ASD symptoms for intervention group with TAU than control group with TAU. Mental health professionals in Rwanda may focus on providing supportive family focused training intervention targeting specific capabilities and competencies for autistic children. Use of FASSA interventions generates new local knowledge (Rwandan context) about ASD and can be integrated in the curricula of undergraduate nurses in health sciences and in service training for health professionals in Rwanda. These findings can be useful by Ministry of Health in Rwanda for developing policies, plans, strategies and appropriate family training programs aiming at reducing of ASD symptoms in Rwandan children. This in return will play important role in the improvement of the well-being of children with ASD and families. Moreover, FASSA would be considered feasible, acceptable and potentially effective in other SSA countries.

CHAPTER VI. SUMMARY OF THE STUDY

6.1. Summary of the Study (English version)

ASD is characterized by abnormalities in reciprocity and interactive communication, stereotypical behavior, and activities interfering with life routines (APA, 2013). Empirical studies were conducted for re-evaluation of children with ASD in Rwanda (*chapter II/study 1*), identification of challenges and coping strategies for parents and clinicians in caring for Children with ASD (*chapter III/ study 2*), as well as Pilot and feasibility Randomized controlled trial (*chapter IV/ study 3*).

Study 1 research questions of the first objective were; does a difference exist between the means scores of participants groups (mothers and children with ASD) relating to socio-demographic factors, achieved on CARS-2 and CASD? The second research question of the second objective was; does CARS-2 and CASD reliably assess ASD symptoms? While the research question of the third objective was “Does childhood rating scale version 2 correlate with the checklist autism rating scale in the assessment of children with ASD in Rwanda?

A convenient sampling strategy was used to achieve a total sample of 94 children with ASD reassessed by the principal investigator (PI) to confirm the ASD diagnosis. A socio-demographic form was utilized to yield socio-demographic data while CARS-2 and CASD were applied for the diagnosis of ASD symptoms by the principal investigator. For analysis of data, descriptive statistics, the independent- samples t-tests and analysis of variance (ANOVA) and the Pearson’s r were used. Parents of children with ASD had signed written informed consent prior to the research. Results of the study 1 revealed, firstly, no association between socio-demographic factors and the severity of ASD symptoms. Only birth condition and mothers age at birth child were associated with ASD symptoms. Secondly, positive large correlation between score achieved on CARS-2 and CASD indicating that an increase in severity of ASD symptoms as measured by CARS-2 results in an increase in severity of ASD symptoms as measured by CARS-2. These results are consistent with studies conducted that indicated correlation between CARS-2 and CASD.

The *study 2* research questions were; (1) What are challenges faced by parents of Children with ASD and clinicians caring for the Children with ASD in Rwanda? (2) What are coping strategies adopted by parents of Children with ASD and clinicians in managing Children with ASD in Rwanda?

This study was conducted on twenty (n = 20) parents of children with and twenty (n =20) clinicians caring children with ASD. The researcher conducted an in-depth semi-structured, interview with parents of Children with ASD and clinicians to collect data. NVivo12 software program (QSR International) was utilized to analyze data. The study 2 results revealed, firstly, a number of challenges faced by ASD mothers pertaining the child's ASD condition, which were; lack of knowledge, financial and caring burden, stigma and frustration, and secondly, parents' coping strategies which consisted of self-informing, respite services, reliance on supernatural power, acceptance and consultation of extended family and clinicians at health facilities. On the part of clinicians, the study reported firstly, their obstacles in managing Children with ASD which were; lack of knowledge, overwork, social interaction barriers with Children with ASD, and secondly, their coping strategies in managing Children with ASD, which were; Self-informing and team work with colleagues. The results are consistent with studies conducted by other authors in previous studies. However, the current study brings new information into the literature on involvement of the extended family as a coping strategy, represented by grandparents or any important figures in the extended family, namely the chief of family where relevant.

Finally, *study 3* is a feasibility study which targeted on adapting the existing evidence based intervention for the management of Children with ASD developed in India (Brief parent mediated intervention for children with ASD)(Manohar et al., 2019). The adapted model was Family Focused Training therapeutic model for caring children with ASD in Sub-Sahara Africa (FASSA). The research questions were; (1) What is the attrition and attendance rate of families during the family focused training care model for children with ASD in Sub Sahara Africa (FASSA) in Rwanda? (2) Are families compliant with FASSA in Rwanda? (3) Is there a difference in symptoms reduction between the children who receive FASSA in Rwanda and those who do not receive the FASSA in Rwanda?

The study 3 used interventional study design, a clinical trial which had parallel assignment, consisting of 21 children with ASD in intervention group and 21 children with ASD in the control group. Confirmed Children with ASD, 4-12 years from study 1, and their families who were available and consented to participate in this study, were randomly assigned to 2 groups. Both groups were under TAU where it was applicable. The sample size of 42 children with ASD was obtained by simple random sampling. Measures of feasibility and acceptability were (1) Home logbook, (2) SRS and CORS to assess family compliance (3) CARS-2 and CASD to evaluate reduction of ASD symptoms. The FASSA was a two weekly based training sessions (*session1*: psychoeducation; *session 2*: Joint attention, *session 3*: Imitation; *session 4*: social skills and *session 5*: Adaptive skills) conducted by the therapist (PI) during 3 months.

The study 3 demonstrated high participant's compliance with treatment as indicated by the attrition rate of 2.38% (*n=1*), overall attendance of 98.5%, training sessions completed 100% and the average parents training hours of 13.4hrs/14hrs (95.7%). This compliance was measured by SRS during the participants' training sessions and the report on children outcome measured by CORS showed some improvement with time progression. Moreover, study 3 presented a reduction in ASD symptoms scores across the three periods, the baseline, end therapy and follow up assessments with large effect size of .54 on CARS-2 and large effect size of .58 on CASD. The difference between the effectiveness of the two groups together with a very large effect size was observed, i.e., .17 for CARS-2 and large effect size of .21 for CASD.

The present study displayed family compliance with the intervention program and large numerical changes in scores achieved on CARS2, indicating significant improvement on children outcomes and symptoms which could have motivated and increased parental engagement. These findings are consistent with different studies on brief intervention for Children with ASD conducted in natural environments. Family intervention gives family members opportunities to learn about ASD, to contribute towards the caring of the child with ASD and integrate these acquired skills into family routines. This leads to improvement of ASD symptoms and related stress among family members. The overall limitations of the present dissertation included small sample size which does not allow the study to generalized. Also, participants (parents) might be biased due to psychological and emotional status and their expectations they may have to any initiative for their children.

CHAPTER VI. SUMMARY OF THE STUDY

6.2. Summary of the study (German version)

ASD ist gekennzeichnet durch Abweichungen in der Kommunikation, durch stereotypes Verhalten und Aktivitäten, die den Alltagbeeinträchtigen (APA, 2013). Empirische Studien wurden zur Neubewertung von Kindern mit ASD in Ruanda (*Kapitel II/ studie 1*), zur Identifizierung von Herausforderungen und Bewältigungsstrategien für Eltern und Kliniker bei der Betreuung von Kindern mit ASD (*Kapitel III/ studie 2*) sowie zur Pilot- und Machbarkeitsstudie (*Kapitel IV/ studie 3*), einer randomisierten kontrollierten Studie, durchgeführt.

Die Forschungsfragen der Studie 1 im Rahmen des ersten Ziels lauteten: Gibt es einen Unterschied zwischen den Mittelwerten der Teilnehmergruppen (Mütter und Kinder mit ASD) in Bezug auf ihre soziodemografischen Faktoren, die in CARS-2 und CASD erzielt wurden? Die zweite Forschungsfrage des zweiten Ziels lautete: Erfassen CARS-2 und CASD zuverlässig ASD-Symptome? Die Forschungsfrage des dritten Ziels lautete: "Korreliert die Childhood Rating Scale Version 2 mit der Checklist Autism Rating Scale bei der Beurteilung von Kindern mit ASD in Ruanda?

Übersetzt mit www.DeepL.com/Translator (kostenlose Version) Es wurde eine willkürliche und zielgerichtete Stichprobenstrategie genutzt, um eine Gesamtstichprobe von N = 94 Kindern zu erhalten, erneute Beurteilung durch den Hauptprüfer (PI) zur Bestätigung der ASD-Diagnose. Zur Erfassung der soziodemografischen Daten wurde ein soziodemografisches Formular verwendet, während CARS-2 und CASD zur Diagnose der ASD-Symptome durch den Untersuchungsleiter eingesetzt wurden. Zur Analyse der Daten wurden deskriptive Statistiken, t-Tests für unabhängige Stichproben, Varianzanalysen (ANOVA) und das Pearson's r verwendet. Die Eltern von Kindern mit ASD hatten vor der Untersuchung eine schriftliche Einverständniserklärung abgegeben. Die Ergebnisse der Studie 1 ergaben erstens keinen Zusammenhang zwischen soziodemografischen Faktoren und dem Schweregrad der ASD-Symptome. Nur die Geburtsbedingungen und das Alter der Mutter bei der Geburt des Kindes wurden mit ASD-Symptomen in Verbindung gebracht. zweitens eine große positive Korrelation zwischen der bei CARS-2 erreichten Punktzahl und CASD, was darauf hindeutet, dass eine Zunahme des Schweregrads der ASD-Symptome, gemessen durch CARS-2, zu einer Zunahme des Schweregrads der ASD-Symptome, gemessen durch CARS-2, führt. Diese Ergebnisse stehen im Einklang mit Studien, die auf eine Korrelation zwischen CARS-2 und CASD hinweisen.

Studie 2 konzentrierte sich auf die Ermittlung von Herausforderungen und Bewältigungsstrategien von Eltern von Kindern mit ASS und Klinikern, die Kinder mit ASS betreuen. Die Forschungsfragen lauteten: (1) Welchen Herausforderungen sehen sich Eltern von Kinder mit ASS und Kliniker, die Kinder mit ASS in Ruanda betreuen, gegenüber? (2) Welche Bewältigungsstrategien werden von Eltern von Kindern mit ASS und Klinikern beim Umgang mit Kindern mit ASS in Ruanda angewandt?

Diese Studie wurde mit zwanzig (n = 20) Eltern von Kindern mit ASD und zwanzig (n = 20) Klinikern, die Kinder mit ASD betreuen, durchgeführt.. Zur Datenerhebung führte der Untersucherein ausführliches halbstrukturiertes Interview mit Eltern von Kinder mit ASSn und Klinikern. Zur Analyse der Daten wurde das Softwareprogramm NVivo12 (QSR International) verwendet.

Die Ergebnisse der Studie 2 zeigten, dass Mütter von Kindern mit ASS vor allem mit folgenden Herausforderungen konfrontiert:mangelndes Wissen, finanzielle und fürsorgliche Belastung, Stigmatisierung und Frustration. Die Bewältigungsstrategien der Eltern sind: Selbstinformation, Entlastungsdiensten, Vertrauen auf übernatürliche Kräfte, Akzeptanz und Beratung durch die erweiterte Familie und Ärzte in Gesundheitseinrichtungen. Von Seiten der Kliniker wurden in der Studie erstens ihre Hindernisse im Umgang mit Kindern mit ASS genannt, nämlich: Mangel an Wissen, Überlastung, Barrieren in der sozialen Interaktion mit Kindern mit ASS, und zweitens ihre Bewältigungsstrategien im Umgang mit Kindern mit ASS, nämlich: Selbstinformation und Teamarbeit mit Kollegen. Die Ergebnisse stimmen mit den Untersuchungen anderer Autoren in früheren Studien überein. Die vorliegende Studie ergibt jedoch neue Informationen für die Literatur über das Einbeziehen der erweiterten Familie als Bewältigungsstrategie. Die erweiterte Familie wird durch Großeltern oder jegliche andere wichtige Person repräsentiert, insbesondere durch das Familienoberhaupt, wo relevant.

Bei Studie 3 schließlich handelt es sich um eine Machbarkeitsstudie, die darauf abzielt, die in Indien entwickelte, evidenzbasierte Intervention für die Behandlung von ASD-Kindern zu adaptieren (Brief parent mediated intervention for children with ASD)(Manohar et al., 2019). Die Forschungsfragen lauteten: (1) Wie hoch ist die Fluktuations- und Teilnahmequote von

Familien während des familienorientierten Trainingsmodells für Kinder mit ASD in Subsahara-Afrika (FASSA) in Ruanda? (2) Sind die Familiendie Intervention? (3) Gibt es einen Unterschied in der Symptomreduzierung zwischen den Kindern, die FASSA in Ruanda erhalten, und denen, die kein FASSA in Ruanda erhalten?

In dieser Studie wurden interventionelle Studiendesign verwendet, eine klinische Studie mit paralleler Zuordnung, bestehend aus 21 Kindern mit ASD in der Interventionsgruppe und 21 Kindern mit ASD in der Kontrollgruppe. Kinder mit bestätigter ASS Diagnose im Alter von 4-12 Jahren (gleiche Stichprobe wie Studie 1) und ihre Familien, die für die Teilnahme an dieser Studie zur Verfügung standen und damit einverstanden waren, wurden nach dem Zufallsprinzip 2 Gruppen zugeteilt. Beide Gruppen waren unter TAU, wo es anwendbar war. Zur Beurteilung der Durchführbarkeit und Akzeptanz wurden (1) ein häusliches Logbuch, (2) Session Rating Scale (SRS) und Child Outcome Rating Scale (CORS) zur Bewertung der Compliance der Familie und (3) Childhood Autism Rating Scale (CARS-2) und Checklist for Autism Spectrum Disorder (CASD) zur Bewertung der Verringerung der ASD-Symptome herangezogen. Das FASSA-Programm bestand aus zwei wöchentlichen Trainingseinheiten (Sitzung 1: Psychoedukation; Sitzung 2: Gemeinsame Aufmerksamkeit, Sitzung 3: Nachahmung; Sitzung 4: Soziale Fähigkeiten und Sitzung 5: Adaptive Fähigkeiten), die vom Therapeuten (PI) drei Monate lang durchgeführt wurden.

Die Studie 3 zeigte eine hohe Therapietreue der Teilnehmer, wie die Abbruchrate von 2,38 % (n=1), die Gesamtanwesenheit von 98,5 %, die zu 100 % abgeschlossenen Übungssitzungen und die durchschnittlichen Übungsstunden der Eltern von 13,4 Stunden/14 Stunden (95,7 %) belegen. Die Umsetzungstreue/Compliance wurde mit der Session Rating Scale (SRS) während der Trainingsstunden mit den Teilnehmenden erfasst und der Bericht über die Ergebnismessung auf Seiten der Kinder mit der Child Outcome Rating Scale (CORS). Der CORS zeigte einige Verbesserungen mit fortschreitender Zeit.. Darüber hinaus zeigte sich in Studie 3 eine Verringerung der ASD-Symptome in allen drei Zeiträumen, d. h. zu Beginn, am Ende der Therapie und bei der Nachuntersuchung, mit einer großen Effektgröße von *d* = .54 bei CARS-2 und einer großen Effektgröße von .58 bei CASD. Der Unterschied zwischen der Wirksamkeit der beiden Gruppen wurde zusammen mit einer sehr großen Effektgröße beobachtet, d. h. .17 für CARS-2 und eine große Effektgröße von .21 für CASD.

CHAPTER VI. SUMMARY OF THE STUDY

In der vorliegenden Studie zeigte sich, dass die Familie das Interventionsprogramm befolgte und große numerische Veränderungen bei den CARS2-Werten erzielt wurden, was auf eine signifikante Verbesserung der Ergebnisse und Symptome bei den Kindern hindeutet, was das elterliche Engagement motiviert und verstärkt haben könnte. Diese Ergebnisse stehen im Einklang mit verschiedenen Studien über Kurzinterventionen bei Kindern mit ASD, die in natürlicher Umgebung durchgeführt wurden. Die Familienintervention bietet Familienmitgliedern die Möglichkeit, etwas über ASD zu lernen, zur Betreuung des Kindes mit ASD beizutragen und die erworbenen Fähigkeiten in die Familienroutine zu integrieren. Dies führt zu einer Verbesserung der ASD-Symptome und des damit verbundenen Stresses bei den Familienmitgliedern.

CHAPTER VI. SUMMARY OF THE STUDY

VII. BIBLIOGRAPHY

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APPENDICES

Appendix 1: Research instruments

1.1. Sociodemographic form

Instruction: Answer each question, provide information about you and your child

	Question	**Information provided**
	I. Personal (Child) information	
1	Province	
2	District	
3	Sector	
4	Cell	
5	Village	
	II. Personal (Child/adolescent) information	
6	Age	
7	Gender	
8	Oder of birth	
11	School attendance	
12	School performance	
13	Relationship with others	
14	The child development history	
15	Birth condition/ birth complication	
	Asphyxia	
	Other: specify	
	III. Parent (Mother or father)/ caregivers	
16	Age in years	
19	Education	
20	Occupation	
21	Number of children	
22	Having mental disorder	
23	Socioeconomic status/ Ubudehe category	

Signature______________________________ Date ___________________________________

Therapist:_________________________

Thank you for your participation

1.2. Childhood rating scale version 2 (CARS-2)

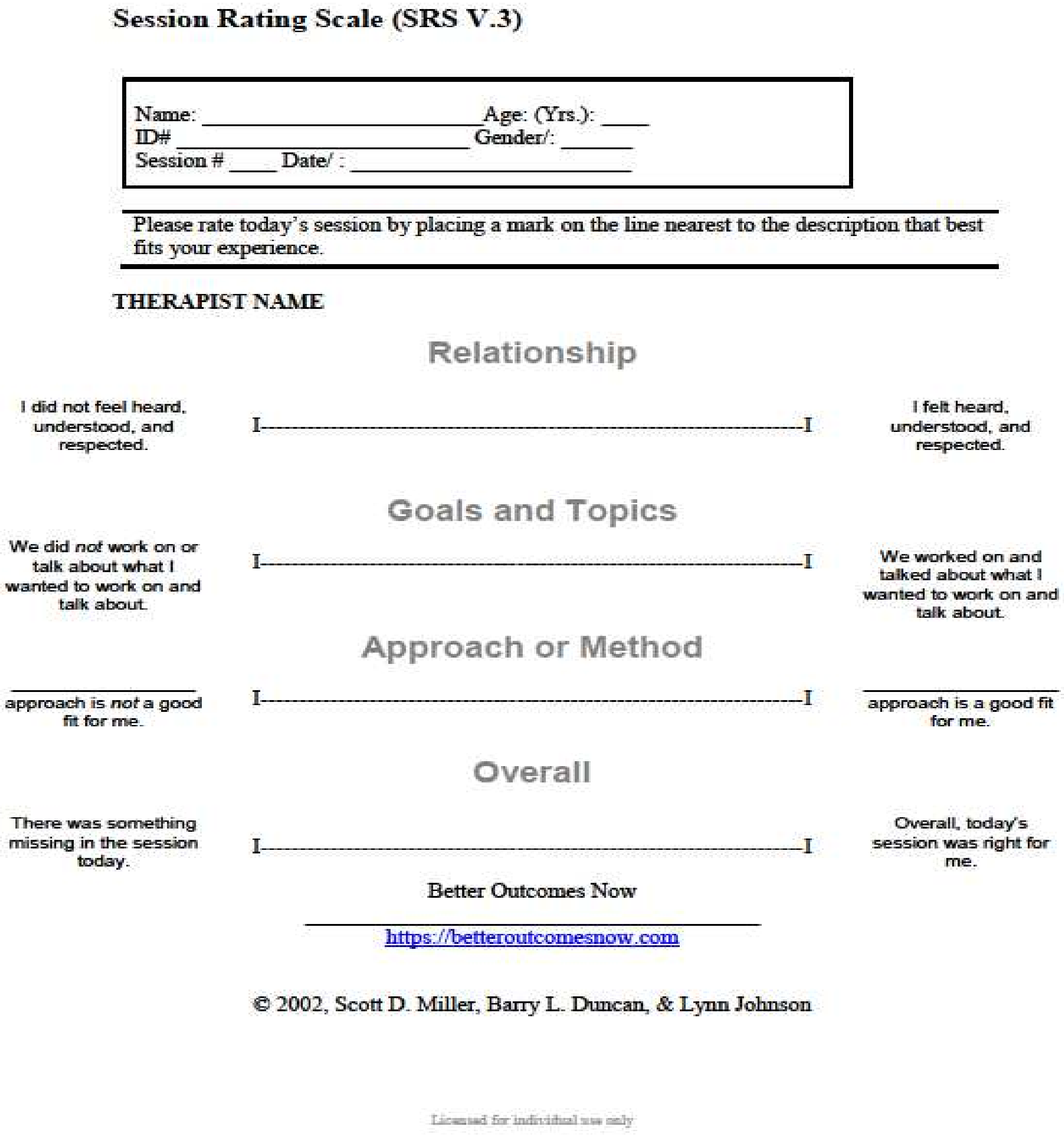
Item number	**Items**				
1	Relating with people	1	2	3	4
2	Imitation	1	2	3	4
3	Emotional responses	1	2	3	4
4	Body use	1	2	3	4
5	Object use	1	2	3	4
6	Adaptation to change	1	2	3	4
7	Visual response	1	2	3	4
8	Listening response	1	2	3	4
9	Taste, smell & touch response and use	1	2	3	4
10	Fear or nervousness	1	2	3	4
11	Verbal communication	1	2	3	4
12	Nonverbal communication	1	2	3	4
13	Activity level	1	2	3	4
14	Level of consistency of intellectual responses	1	2	3	4
15	General impressions	1	2	3	4
	Total score				

1.3. Checklist for autism spectrum disorder (CASD)

Items	Items	Yes	No
1	Social isolation		
2	Limited reciprocal interaction		
3	Self-absorbed		
4	Socially indiscriminate behavior		
5	Problems with social skills		
6	Narrow or unusual range of interests and play behaviors		
7	Stereotyped and repetitive play		
8	Upset with change		
9	Stereotypies		
10	Excessive atypical craving and love of spinning, climbing, rocking, swinging, bouncing, jumping		
11	Unresponsive at times to verbal input		
12	Hypersensitivity		
13	Distress with commotion or crowds		
14	Extreme fascination with spinning or repetitive movements linear patterns, minute details, lights, shiny surfaces		
15	Abnormal sensory inspection		
16	Tactile defensiveness		
17	High tolerance for pain		
18	Sleep disturbance		
19	Feeding problems		
20	Language regression or slowing at approximately 1 to 2 years of age		
21	Visual-motor skills significantly higher than language skills during the preschool years or walking at a much earlier age than talking		
22	Communication impairment		
23	Atypical vocalizations or speech		
24	Special abilities that are significantly higher than other abilities		

25	Over-reactivity, irritability, low frustration tolerance, agitation, tantrums, meltdowns, explosiveness, aggression, or self-injurious		
26	Moodiness and emotional lability (the cause for mood changes may not always apparent, such as laughter or distress for no apparent reason)		
27	Difficulty showing and recognizing emotions, emotionally unresponsive in some situations, lack of empathy or emotional reciprocity or misinterprets the emotions or responses of others		
28	Unusual fears, such as fear of elevators, steps, toilets, balloons, vacuums, tornadoes, other_____		
29	Selective attention, ability to hyperfocus on activities, objects, or topics of interest to self but is inattentive, impulsive, and fidgety at other times		
30	Limited safety awareness, fearless, or oblivious to danger		

1.4. Session rating scale (SRS)



Session Rating Scale (SRS V.3)

Name: ________________________Age: (Yrs.): ____
ID# _________________________ Gender/: ______
Session # ____ Date/ : ________________________

Please rate today's session by placing a mark on the line nearest to the description that best fits your experience.

THERAPIST NAME

Relationship

I did not feel heard, understood, and respected.

I---I

I felt heard, understood, and respected.

Goals and Topics

We did *not* work on or talk about what I wanted to work on and talk about.

I---I

We worked on and talked about what I wanted to work on and talk about.

Approach or Method

________________ approach is *not* a good fit for me.

I---I

________________ approach is a good fit for me.

Overall

There was something missing in the session today.

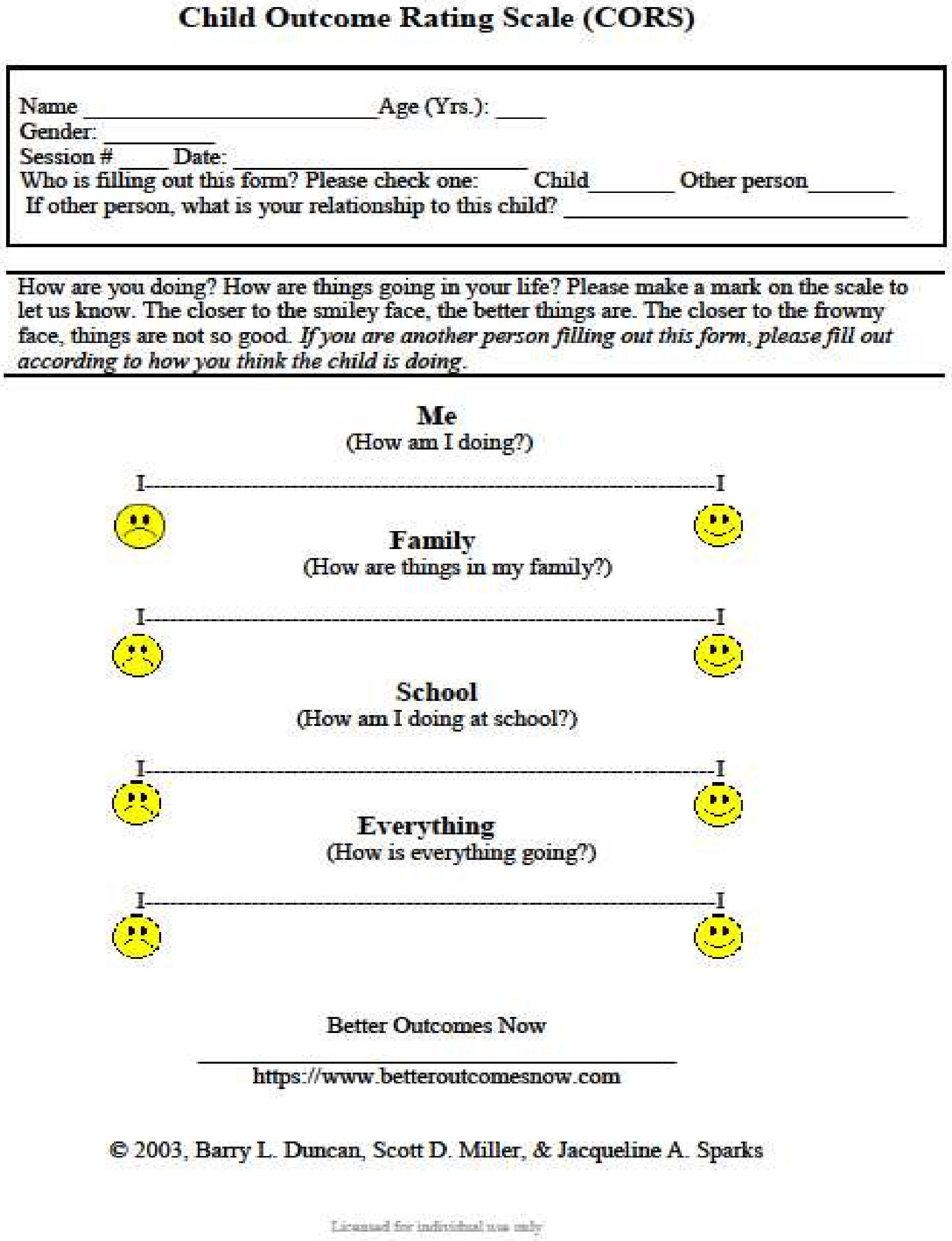
I---I

Overall, today's session was right for me.

Better Outcomes Now

https://betteroutcomesnow.com

1.5. Child outcome rating scale (CORS)



Child Outcome Rating Scale (CORS)

Name ________________________Age (Yrs.): ____
Gender: _________
Session # _____ Date: ________________________
Who is filling out this form? Please check one: Child_______ Other person_______
If other person, what is your relationship to this child? ____________________________

How are you doing? How are things going in your life? Please make a mark on the scale to let us know. The closer to the smiley face, the better things are. The closer to the frowny face, things are not so good. *If you are another person filling out this form, please fill out according to how you think the child is doing.*

Me
(How am I doing?)

I--I
☹ ☺

Family
(How are things in my family?)

I--I
☹ ☺

School
(How am I doing at school?)

I--I
☹ ☺

Everything
(How is everything going?)

I--I
☹ ☺

Better Outcomes Now

https://www.betteroutcomesnow.com

1.6. **Interview guide for parents of children with ASD (English version)**

Key points that will be explored during the interviews: Recognition of Autism Spectrum Disorder (ASD)(symptoms, the diagnosis process, services provided-treatment and interventions), challenges faced, coping actions and wishes/ suggestions.

Interview questions and prompts

1. Can you tell me about your experiences of first observing something of concern with your child behavior changes?

i. Tell me about first reaction after observing your child behavior changes.

ii. If not mentioned, the following are prompts regarding the first reaction after observing the child behavior changes: Tell me about the following items in regards of the first reaction after observing the child behavior changes.

a. Discussion in family for making decision?

b. Consulting community health workers/ local authorities?

c. Seeking for assistance from health facilities?

d. Seeking for assistance from traditional healers? Tell me about traditional healers in your community or everywhere in Rwanda.

iii. Tell me about the diagnosis process.

iv. Can you describe services provided to your child?

2. Tell me about the relationships between your child with maladaptive behavior and siblings, you, your husband, chief of the family and grandparents, if applicable?

3. Tell me about challenges, if any, that you have faced for caring your child?

If not mentioned, the following are prompts regarding the challenges faced by the parent:

a. ASD knowledge

b. Child/ adolescent related challenges (behavior, school, friends etc)

c. Being a parent to a child with autism.

d. A family

e. Community (for example; stigma, traditional healers, others)

f. Health facility (s)

g. others

4. Tell me about what you did to overcome these challenges

5. Tell me about wishes to other parents with a child like yours in Rwanda, to improve the quality of life of ASD child and her/ his family well-being? What wishes would you like to give to health professionals caring for children like yours in health facilities in Rwanda, to meet Children with ASD needs?

Thank you very much for your interview

2. Challenges and coping strategies of clinicians caring children with ASD in Rwanda: Codes, subthemes and themes

2.1. Codes, subthemes and themes for clinicians

Codes	Sub themes	Themes
child mute; difficult living with others; own ways of doing things; inability to dialogue	Communication barriers	Challenges faced by clinicians for caring children with ASD
discouragement; hopeless; lack of materials; anxious; shame; difficult of meeting people's expectations; impatience; no alternative care	Frustration	
Confusion; confirmation of the illness; insufficient knowledge and skills on ASD; no medicines	Lack of knowledge	
work overload; Tiredness; Difficult; many duties and responsibilities	Overworking	
equipping each other; peers consultation with specialist	Team work	Coping strategies to challenges faced by clinicians for caring children with ASD
reading books; internet based search	Self-informing	

2.2. Challenges and coping strategies of parents of children with ASD in Rwanda: Codes, subthemes and themes for parents

Codes	Sub themes	Themes
Discrimination wife blaming family shame; culture condemning terminology; unacceptance; parental low self-esteem;	1. Stigma and discrimination	Challenges faced by parents for caring children with ASD
Expensive special needs education; prohibitive costs of medication; housemaid; inability to hire a home teacher; Increased caring responsibility; difficulty coping with child's behavior; hard to meet basic needs; parental overburden; strenuous to care for the child; caring overwhelming; quitting a job difficult; prohibitive special diet	2. Financial & caring burden	
Deficient knowledge about autism deficient knowledge and skills for handling ASD; short of caring skills; not sure on how to behave towards Children with ASD; deficient knowledge on treatment; ill-informed about care;	3. Lack of knowledge	
Discouragement from family members; anxiety about the child's life; lose hope; shame; embarrassment;	4. Parent frustration	

unhappiness; Stress		
Accepting the ASD child; accepting the situation; readiness for everything	1. Accepting	Coping strategies to challenges faced by the parents of children with ASD
Prayers traditional healers: belief in witchcraft;	2. Reliance on supernatural power	
searching for the ASD care institution; enrolling the child in school;	3. Respite services	
Group support; internet search; reading text books; movies information; regular learning effort;	4. Self-informing	
Extended family consultations; medical staff consultations; attending medical institutions;	5. Consultation with family members and health settings	

3. Training materials

3.1. List of activities and their scripts according to training sessions

S/C	Training sessions	Activities	Participants	Materials	Scripts
1	Psycho-education	Discussion	Parents, ASD child, siblings and other people living in family	Leaflet	NA
2	Joint attention training - Pointing - Eye contact	1. Arranging thinks according to colors	Parents, ASD child, siblings and other people living in family	Pieces of paper in different colors,	o Bring pieces of papers or other objects (cards) in different colors o Explanation of activity o Ask participants to show (by pointing) different colors represented o Ask each participant to arrange the papers or other objects (cards) according to different colors o Ask each participant to rearrange the papers or other objects (cards) according to different colors o Repeat the activity as many as possible (the target will be mainly placed on the ASD child).

					○ If needed, prompt the ASD child to accomplish the activity. ○ Reward the ASD child for his/ her effort made ○ End the activity
		2. Hide and seek game	Parents, ASD child, siblings and other people living in family	Coins or any material interesting the child.	○ Bring coins or any materials interesting the child ○ Explanation of activity ○ Ask the participants to perform the hide and seeking game. ○ Look at every face and make every one eyes contact ○ Hide a coin or any other object in one hand ○ Choose a partner to discover the coin or the object ○ Discover which hand contains the coins or the object. ○ Decide to the participant who will win the others (the target will be mainly placed on the ASD child) ○ Repeat the activity many times as possible

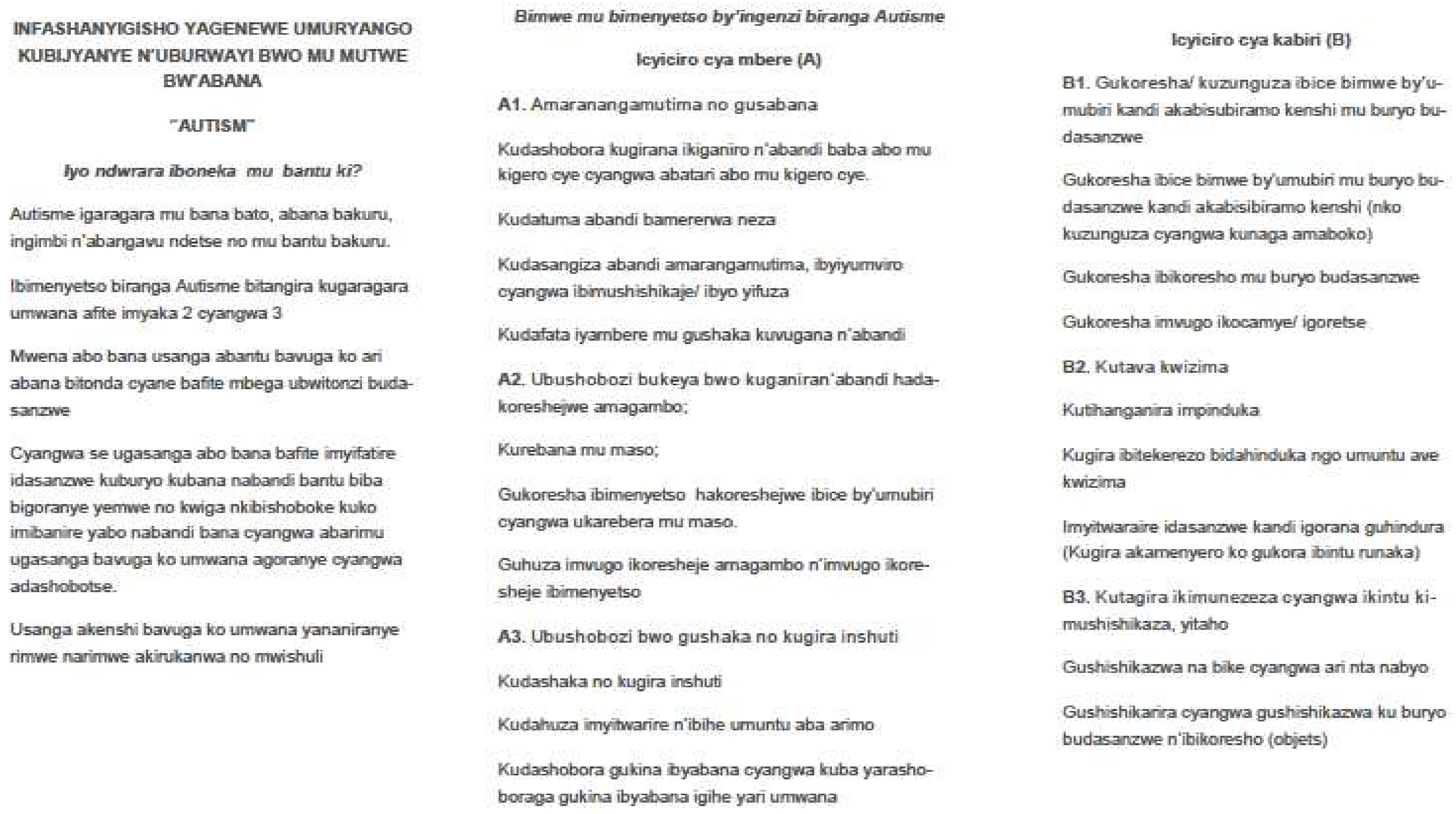
					○ If needed prompt the ASD child to accomplish the activity ○ Reward the ASD child for his/ her effort made ○ End the activity
3	Imitation training - Motor imitation - Verbal imitation	1.Simple physical exercise	Parents, ASD child, siblings and other people living in family	None	○ Explanation of activity ○ Revise previous activities ○ Relaxing by asking each participant to find out a simple physical exercise to be imitated ○ Demonstrate the simple physical exercise ○ Imitation by other participants ○ Repeat the activity many times as possible ○ If needed prompt the ASD child to accomplish the activity ○ Reward the ASD child for his/ her effort made ○ End the activity
		2. Name home routine materials	Parents, ASD child, siblings and other people living in family	Drawings of home routine materials and other things in	○ Bring drawings of home materials around ○ Explanation of activity ○ Name the home materials around

				the environment of the child	o Children (ASD child and siblings) repeat the name of the home material as expressed by parents o Repeat the activity many times as possible o If needed prompt the ASD child to accomplish the activity o Reward the ASD child for his/ her effort made o End the activity
4	Social engagement training - Greeting/ Requesting - Turn taking games	1. Name, find and request the materials used at home	Parents, ASD child, siblings and other people living in family	Drawings of home routine materials	o Bring drawings of home materials around o Explanation of activity o Name the home materials around o Request children (ASD child and siblings) repeat the name of the home material as expressed by parents o Children (ASD child and siblings) repeat the name of the home material as expressed by parents o Repeat the activity many times as possible o If needed prompt the ASD child to accomplish the activity o Reward the ASD child for his/ her effort made

					o End the activity
		2. Game of Lancing a ball in basket	Parents, ASD child, siblings and other people living in family	A basket and the ball	o Prepare materials o Explain the activity o Turn taking game by lancing a ball in a basket o Repeat activity o Decide to the participant who will win the others (the target will be mainly placed on the ASD child) o If needed prompt the ASD child to accomplish the activity o Reward the ASD child for his/ her effort made o End the activity
5	Adaptive skills training	1. Hand washing	Parents, ASD child, siblings and other people living in family	Water, basket (or any other container), cup or a jag, essui main, and soap.	o Prepare materials o Explain the task o Put water in basket o Wash hand by water o Apply soap o Clean the soap o Dry the hands by essui- main o Throw the used water

					○ Repeat the activity as much as possible ○ If needed prompt the ASD child to accomplish the activity ○ Reward the ASD child for his/ her effort made ○ End the activity
		2. Exercise on dressing (clothes and shoes)	Parents, ASD child, siblings and other people living in family	Clothes and shoes	○ Prepare materials ○ Explain the task ○ Inserting lacet if available ○ Wearing clothes or shoes ○ Repeat the activity as much as possible ○ If needed prompt the ASD child to accomplish the activity ○ Reward the ASD child for his/ her effort made ○ End the activity

3.2. Psychoeducation Brochure



INFASHANYIGISHO YAGENEWE UMURYANGO KUBIJYANYE N'UBURWAYI BWO MU MUTWE BW'ABANA

"AUTISM"

Iyo ndwrara iboneka mu bantu ki?

Autisme igaragara mu bana bato, abana bakuru, ingimbi n'abangavu ndetse no mu bantu bakuru.

Ibimenyetso biranga Autisme bitangira kugaragara umwana afite imyaka 2 cyangwa 3

Mwena abo bana usanga abantu bavuga ko ari abana bitonda cyane bafite mbega ubwitonzi budasanzwe

Cyangwa se ugasanga abo bana bafite imyifatire idasanzwe kuburyo kubana nabandi bantu biba bigoranye yemwe no kwiga nkibishoboke kuko imibanire yabo nabandi bana cyangwa abarimu ugasanga bavuga ko umwana agoranye cyangwa adashobotse.

Usanga akenshi bavuga ko umwana yananiranye rimwe narimwe akirukanwa no mwishuli

Bimwe mu bimenyetso by'ingenzi biranga Autisme

Icyiciro cya mbere (A)

A1. Amaranangamutima no gusabana

Kudashobora kugirana ikiganiro n'abandi baba abo mu kigero cye cyangwa abatari abo mu kigero cye.

Kudatuma abandi bamererwa neza

Kudasangiza abandi amarangamutima, ibyiyumviro cyangwa ibimushishikaje/ ibyo yifuza

Kudafata iyambere mu gushaka kuvugana n'abandi

A2. Ubushobozi bukeya bwo kuganiran'abandi hadakoreshejwe amagambo;

Kurebana mu maso;

Gukoresha ibimenyetso hakoreshejwe ibice by'umubiri cyangwa ukarebera mu maso.

Guhuza imvugo ikoresheje amagambo n'imvugo ikoresheje ibimenyetso

A3. Ubushobozi bwo gushaka no kugira inshuti

Kudashaka no kugira inshuti

Kudahuza imyitwarire n'ibihe umuntu aba arimo

Kudashobora gukina ibyabana cyangwa kuba yarashoboraga gukina ibyabana igihe yari umwana

Icyiciro cya kabiri (B)

B1. Gukoresha/ kuzunguza ibice bimwe by'umubiri kandi akabisubiramo kenshi mu buryo budasanzwe

Gukoresha ibice bimwe by'umubiri mu buryo budasanzwe kandi akabisibiramo kenshi (nko kuzunguza cyangwa kunaga amaboko)

Gukoresha ibikoresho mu buryo budasanzwe

Gukoresha imvugo ikocamye/ igoretse

B2. Kutava kwizima

Kutihanganira impinduka

Kugira ibitekerezo bidahinduka ngo umuntu ave kwizima

Imyitwaraire idasanzwe kandi igorana guhindura (Kugira akamenyero ko gukora ibintu runaka)

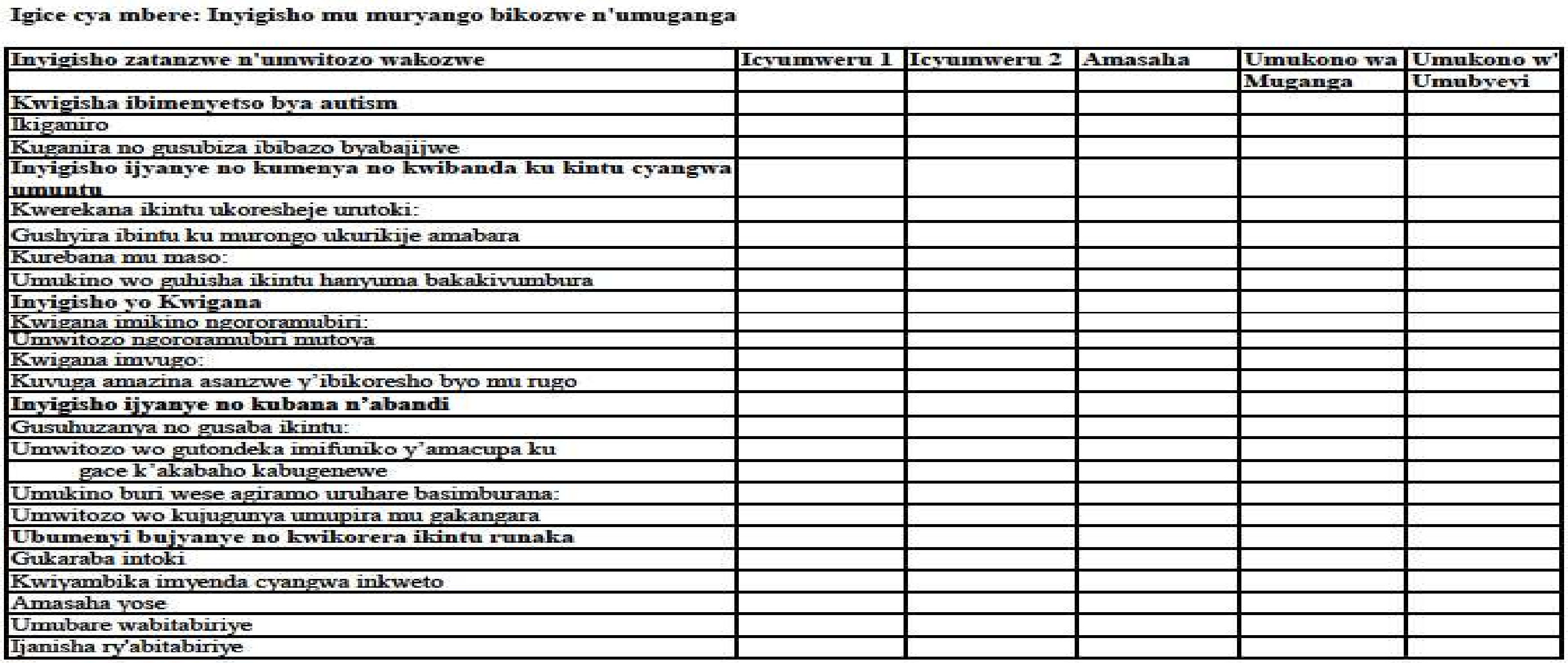
B3. Kutagira ikimunezeza cyangwa ikintu kimushishikaza, yitaho

Gushishikazwa na bike cyangwa ari nta nabyo

Gushishikarira cyangwa gushishikazwa ku buryo budasanzwe n'ibikoresho (objets)

4. Home logbooks

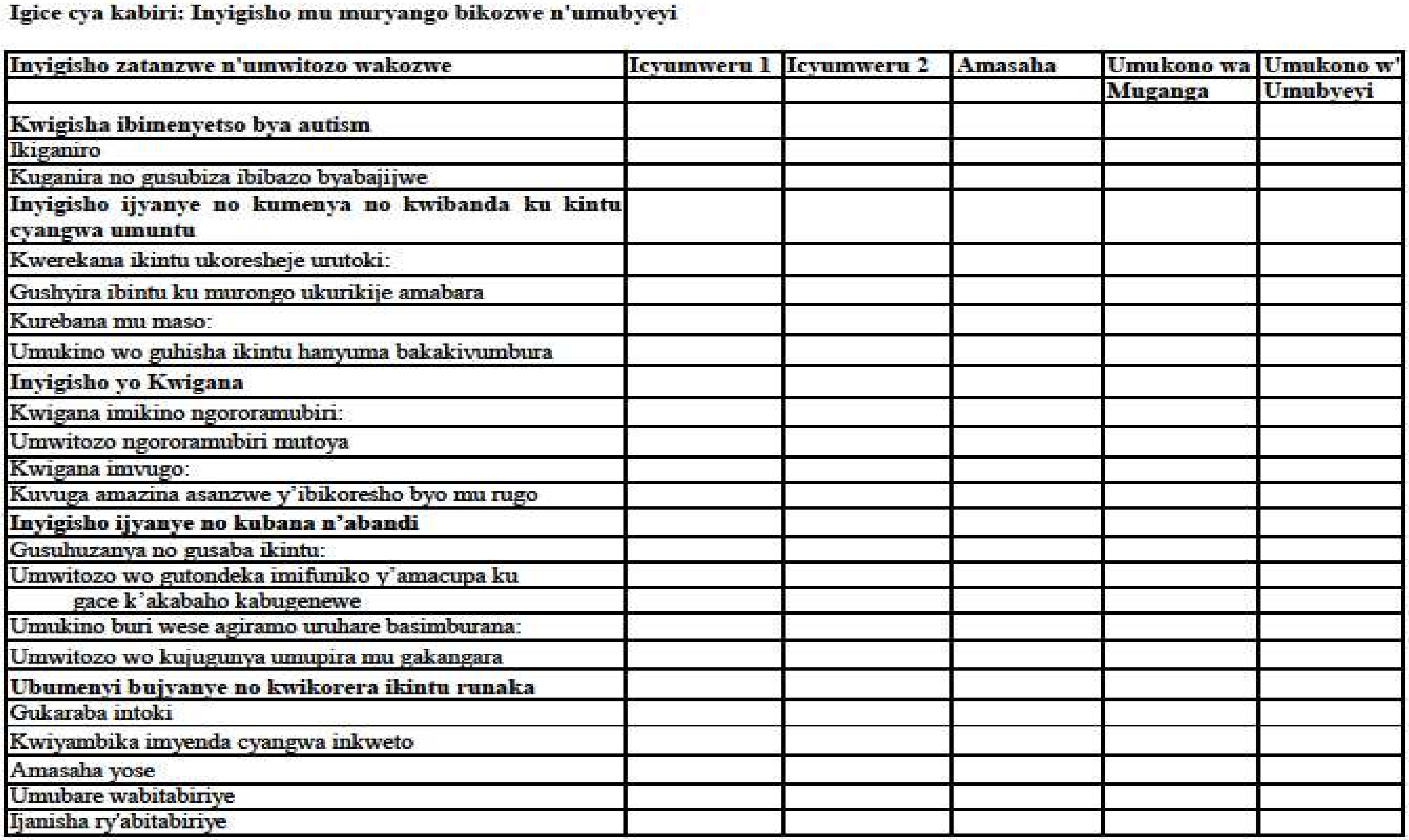
4.1. Home logbook part 1: family training mediated by therapist/PI (weekly)



Igice cya mbere: Inyigisho mu muryango bikozwe n'umuganga

Inyigisho zatanzwe n'umwitozo wakozwe	**Icyumweru 1**	**Icyumweru 2**	**Amasaha**	**Umukono wa Muganga**	**Umukono w' Umubyeyi**
Kwigisha ibimenyetso bya autism					
Ikiganiro					
Kuganira no gusubiza ibibazo byabajijwe					
Inyigisho ijyanye no kumenya no kwibanda ku kintu cyangwa umuntu					
Kwerekana ikintu ukoresheje urutoki:					
Gushyira ibintu ku murongo ukurikije amabara					
Kurebana mu maso:					
Umukino wo guhisha ikintu hanyuma bakakivumbura					
Inyigisho yo Kwigana					
Kwigana imikino ngororamubiri:					
Umwitozo ngororamubiri mutoya					
Kwigana imvugo:					
Kuvuga amazina asanzwe y'ibikoresho byo mu rugo					
Inyigisho ijyanye no kubana n'abandi					
Gusuhuzanya no gusaba ikintu:					
Umwitozo wo gutondeka imifuniko y'amacupa ku					
gace k'akabaho kabugenewe					
Umukino buri wese agiramo uruhare basimburana:					
Umwitozo wo kujugunya umupira mu gakangara					
Ubumenyi bujyanye no kwikorera ikintu runaka					
Gukaraba intoki					
Kwiyambika imyenda cyangwa inkweto					
Amasaha yose					
Umubare wabitabiriye					
Ijanisha ry'abitabiriye					

4.2. Home logbook part 2: family training mediated by parents (Weekly)



Igice cya kabiri: Inyigisho mu muryango bikozwe n'umubyeyi

Inyigisho zatanzwe n'umwitozo wakozwe	Icyumweru 1	Icyumweru 2	Amasaha	Umukono wa Muganga	Umukono w' Umubyeyi
Kwigisha ibimenyetso bya autism					
Ikiganiro					
Kuganira no gusubiza ibibazo byabajijwe					
Inyigisho ijyanye no kumenya no kwibanda ku kintu cyangwa umuntu					
Kwerekana ikintu ukoresheje urutoki:					
Gushyira ibintu ku murongo ukurikije amabara					
Kurebana mu maso:					
Umukino wo guhisha ikintu hanyuma bakakivumbura					
Inyigisho yo Kwigana					
Kwigana imikino ngororamubiri:					
Umwitozo ngororamubiri mutoya					
Kwigana imvugo:					
Kuvuga amazina asanzwe y'ibikoresho byo mu rugo					
Inyigisho ijyanye no kubana n'abandi					
Gusuhuzanya no gusaba ikintu:					
Umwitozo wo gutondeka imifuniko y'amacupa ku gace k'akabaho kabugenewe					
Umukino buri wese agiramo uruhare basimburana:					
Umwitozo wo kujugunya umupira mu gakangara					
Ubumenyi bujyanye no kwikorera ikintu runaka					
Gukaraba intoki					
Kwiyambika imyenda cyangwa inkweto					
Amasaha yose					
Umubare wabitabiriye					
Ijanisha ry'abitabiriye					

APPENDICES