Development of a play-based intervention to promote play skills of children with HIV/Aids living in a low resourced setting

By

Nyaradzai Munambah
DNGNYA002

SUBMITTED TO THE UNIVERSITY OF CAPE TOWN
In fulfilment of the requirements for the degree

PhD

Division of Occupational Therapy

Department of Health and Rehabilitation Sciences

Faculty of Health Sciences

UNIVERSITY OF CAPE TOWN

Date of Submission: 15 March 2021

Supervisors:

Prof Elelwani Ramugondo

Prof Reinie Cordier

Abstract

The lack of contextually relevant conceptual tools to promote play makes implementing play-based, occupation-centred practice challenging for occupational therapists working with children with HIV/Aids in low resourced settings. This doctoral thesis focussed on reviewing and generating evidence, and further proposed a play-based intervention framework for children with HIV/Aids living in a low resourced setting. Theoretical frameworks used to guide the intervention development process and content of the play-based intervention were the United Kingdom Medical Research Council (UK MRC) framework for development and evaluation of complex interventions and Cooper's Model of children's play. The development of the play-based intervention involved four phases: 1) conducting a systematic review, 2) profiling of the play of children with HIV/Aids, 3) drawing perspectives of caregivers through in-depth interviews, and 4) gaining consensus from experts on components to include in the play-based intervention framework.

In phase 1, a systematic review following the PRISMA guidelines was conducted to identify evidence that support the development of play-based interventions. Eighteen studies that focused on play as an outcome and compared the play of children with Special Health Care Needs (SHCN) to that of typically developing children met the eligibility criteria. The Kmet checklist was used to evaluate the methodological quality of the studies included. The systematic review revealed paucity of research on the play of children with SHCN such as those with HIV/Aids.

Phase 2 was undertaken to generate more evidence by comparing the play profiles of 44 children with HIV/Aids aged 4-7 years to that of 52, age and gender matched typically developing children. The children were video-recorded while playing with a playmate at school or clinic and home settings. The Test of playfulness was used to score the videos by two independent raters and the scores were subjected to rasch analysis. A comparison of play profiles revealed that children with HIV/Aids were significantly less playful outdoors as compared to typically developing children ($t(94) = 3.57$, $p = 0.001$). Children with HIV/Aids also had more challenges with social play skills.

In phase 3, contextual understanding of the play of children with HIV/Aids was sought through in-depth interviews with fifteen purposively selected caregivers whose children with HIV/Aids had participated in phase 2 of the study. The interviews were audio-recorded,

transcribed verbatim and analysed thematically. The following four themes emerged: ‘Ubuntu is no more’; ‘survival is primary (chikuru kurarama)’; ‘play affirms that my child is still like other children’; and ‘more is required for a child with HIV’. Caregivers also reported on how contextual factors such as HIV/Aids stigma, poverty and cultural beliefs shaped the play of their children.

In phase 4, findings from phases 1, 2 and 3 were synthesised and presented to experts in the field of play, HIV/Aids and intervention development during a two-round Delphi study. Experts were asked about their opinions and to rate what should be included in the play-based intervention framework. Consensus agreement was reached when at least 70% of Delphi experts rated each item at 3 or higher on a 5-point Likert Scale. Experts agreed on the application of Cooper’s Model of children’s play as a theoretical framework, as well as principles and techniques for the play-based intervention.

This study is the second in occupational therapy to report on the play of children with HIV/Aids. It is the first one to review and generate evidence to support play-based interventions targeted at children with HIV/Aids. Evidence generated in this study showcased the need for occupation-centred, play-based services for children with HIV/Aids, particularly those living in low resourced settings. The play-based intervention proposed is child-led, allowing for physical and active involvement of the child. To increase social interaction and continuity into the home environment, playmates and caregivers must be included. Unique to this play-based intervention is advocacy for more play opportunities, access to nutrition and inclusion of culturally sensitive practices. Future studies should include feasibility on various aspects of the play-based intervention before implementing randomised controlled trials to test the effectiveness of the intervention are conducted.

Declaration

I, **Nyaradzai Munambah,** hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

I empower the university to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

Signature:

Date: 15 March 2021

Declaration: Inclusion of publications

I confirm that I have been granted permission by the University of Cape Town's Doctoral Degrees Board (DDB) to include the following publication(s) in my PhD thesis, and where co-authorships are involved my co-authors have agreed that I may include these publication(s):

Publication 1: Systematic review

Munambah, N., Cordier, R., Speyer, R., Toto, S., & Ramugondo, E. L. (2020). A Systematic Review Comparing the Play Profiles of Children with Special Health Care Needs with Typically Developing Children. *BioMedResearch International.* https://doi.org/10.1155/2020/9582795

Publication 2: Play profiles of children with HIV/AIDS: A comparative study

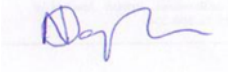
Munambah, N., Cordier, R., Chiwaridzo, M., Ramugondo, E.L. Play profiles of children with HIV/Aids: A comparative study. *Australian Occupational Therapy Journal.* 2020; 00:1–13. https://doi.org/10.1111/1440-1630.12712

Publication 3: Play of children living with HIV/Aids in a low resourced setting: Perspectives of caregivers.

Munambah, N., Ramugondo, E., & Cordier. Play of children living with HIV/Aids in a low resourced setting: Perspectives of caregivers. *British Journal of Occupational Therapy* (Under review)

Publication 4: Play-based intervention guidelines for promoting play in children with HIV/Aids: Delphi Study

Munambah, N., Ramugondo, E., & Cordier. Play-based intervention guidelines for promoting play in children with HIV/Aids: Delphi Study. *Scandinavian Journal of Occupational Therapy* (Under Review)

SIGNATURE:  **DATE: 15 March 2021**

STUDENT NAME: **NYARADZAI MUNAMBAH** STUDENT NUMBER: **DNGNYA002**

Dedication

This thesis is dedicated to all the children living with HIV/Aids and their caregivers in Zimbabwe, who inspired this PhD; and my kids Kunaishe, Kudzaishe and Kudaishe, who gave me the energy to push till the end.

-To God be all the glory-

Acknowledgements

I would like to thank all the caregivers and their children who participated in this study. They sacrificed their time so as to provide invaluable information. Without them, this study was incomplete. Much appreciation goes to the Ministry of Primary and Secondary Education, Harare Province and the Ministry of Health and Child care, who gave permission to access the participants (children and their caregivers) of this study through their systems.

My supervisors, Prof Reinie Cordier and Prof Elelwani Ramugondo, their consistent support throughout the research process is much appreciated. They managed to bring the best out of me. This thesis is a product of their expert advice, constructive criticism, prompt feedback and words of encouragements. The regularly scheduled zoom meetings especially during the COVID-19 pandemic truly paid off.

I also would like to thank my fellow occupational therapists (Rutendo, Kassimir and Pascal) who assisted with data collection. You made the data collection bearable and thus, made it possible to finish data collection within scheduled times. My colleagues in the Department of Rehabilitation, thank you for understanding and accommodating me when I needed protected time to work on this thesis.

Special mention goes to my husband Tawanda and my three children (Kunaishe, Kudzaishe and Kudaishe) who endured lone moments without me. They have been my motivation and pillar of strength throughout the research process.

Table of contents

Abstract i

Declaration iii

Declaration: Inclusion of publications iv

Dedication v

Acknowledgements vi

List of Figures xii

List of Tables xiii

List of Abbreviations xiv

Operational Definitions xv

1 CHAPTER 1: Introduction 17

1.1 Introduction 17

1.2 Background of the study 17

1.3 The context of HIV/Aids in Zimbabwe 19

1.4 Problem statement 20

1.5 Research aim 20

1.6 Purpose of study 21

1.7 Significance of the study 21

1.8 Theoretical Frameworks 22

1.8.1 Model of children's Play 23

1.8.2 The UK MRC Framework 24

1.8.3 Gathering further data 27

1.8.4 Identifying and developing an appropriate theoretical framework 29

1.9 Thesis Outline 29

1.10 Conclusion 30

1.11 References 32

2 CHAPTER 2: Systematic review 36

2.1 Introduction 36

2.2 Background Information 37

2.3 Materials and Methods 40

2.4 Results 44

2.5 Discussion 77
2.6 Limitations of the study 79
2.7 Conclusion and Implications for future research 79
2.8 References 81
3 CHAPTER 3: Play profiles of children with HIV/AIDS 85
3.1 Introduction 85
3.2 Background Information 87
3.3 Methodology 89
3.3.1 Study Design: 89
3.3.2 Research setting: 89
3.3.3 Participants and recruitment 90
3.3.4 Recruitment Procedure 91
3.3.5 Instruments 92
3.3.6 Procedure of data collection 94
3.3.7 Data Analysis 95
3.4 Results 96
3.4.1 Participants: 96
3.4.2 Demographics of the responding caregivers: 99
3.4.3 Play profiles 100
3.4.4 Test of Playfulness item scores: 102
3.4.5 Differences in elements of playfulness based on ToP item scores between HIV+ and TD 105
3.4.6 ToP item scores for Social Skills: 107
3.5 Discussion 108
3.5.1 Indoor versus Outdoor play 108
3.5.2 Elements of play 109
3.5.3 Social play: 110
3.5.4 Contextual Factors 110
3.6 Limitation 112
3.7 Key points for Occupational Therapy 112
3.8 References 113
4 CHAPTER 4: Caregiver's perspectives on play of children with HIV/AIDS 118
4.1 Introduction 118
4.2 Background Information 119
4.3 Play in occupational therapy for children 120

4.4 Play, HIV/Aids and the impact of contextual factors 121
4.5 Methodology 122
4.6 Findings 123
4.6.1 Ubuntu is no more 125
4.6.2 Survival is primary (chikuru kurarama) 127
4.6.3 Play affirms that my child is still like other children 130
4.6.4 More is required for this child 131
4.7 Discussion 132
4.8 Limitations of the study 135
4.9 Conclusion 135
4.10 Key Findings from the study. 135
4.11 What has the study added? 136
5 CHAPTER 5: Delphi Study 139
5.1 Introduction 139
5.2 Background Information 140
5.3 Children's play in the context of HIV/Aids ..... **Error! Bookmark not defined.**
5.4 Conceptual framework: Model of children's play 140
5.5 Play-based interventions 142
5.6 Methodology 143
5.6.1 Study Design 143
5.6.2 Participants and Recruitment 144
5.6.3 Procedures 144
5.6.4 Data Analysis 146
5.7 Results 147
5.7.1 Demographics of the participants 147
5.7.2 Common challenges that limit play in children with HIV/Aids 148
5.7.3 Application of the Children's model of play 148
5.7.4 Principles for the play-based intervention 148
5.7.5 Round Two 149
5.7.6 The pre-intervention learning program 151
5.7.7 Format of presentation of the pre-intervention learning program 151
5.7.8 Delivery of the play-based intervention 151
5.8 Discussion 152
5.8.1 Use of a conceptual framework 152
5.8.2 Principles of intervention 153

5.8.3 Techniques to be used in the intervention 153
5.8.4 Limitations 155
5.9 Conclusion 155
5.10 References 157
6 CHAPTER 6: Discussion and Conclusion 160
6.1 Introduction 160
6.2 Developing a play-based intervention framework 161
6.2.1 Identifying the evidence base 161
6.2.2 Gathering further data 162
6.2.3 Identifying and developing an appropriate theoretical framework 164
6.3 Theoretical framework to guide the play-based intervention: Model of children's play ... 165
6.4 The play-based intervention framework for children with HIV/Aids living in a low resourced setting 169
6.4.1 The play environment 169
6.4.2 Child development capacities 171
6.4.3 Play and playfulness 172
6.4.4 Principles of the play-based intervention framework 173
6.4.5 Techniques/Active ingredients of the play-based intervention framework 178
6.5 Feasibility of the play-based intervention framework 180
6.6 Scope of the research 181
6.7 Strength and Limitations of the study 182
6.8 Recommendations for practice and education 183
6.9 Recommendations for future research 184
6.10 Conclusion 185
6.11 References ..... **Error! Bookmark not defined.**
7 LIST OF APPENDIXES 206
7.1 APPENDIX A: Theoretical Framework: Model of Children's Play 206
7.2 APPENDIX B: Confirmation of Authorship 210
7.3 APPENDIX C: HREC latest renewal 211
7.4 APPENDIX D: HREC Approval letter 212
7.5 APPENDIX E: Approval to use playroom for data collection 213
7.6 APPENDIX F: Approval to recruit participants from Harare Hospital 214
7.7 APPENDIX G: Approval from institutional review board (JREC) 215
7.8 APPENDIX H: Approval from institutional review board (MRCZ) 216
7.9 APPENDIX I: Approval from Ministry of Primary and secondary schools 217

7.10 APPENDIX J: Information letter to caregivers (English) 218
7.11 APPENDIX K: Information letter to caregivers (Shona) 220
7.12 APPENDIX L: Parent Informed Consent form (English) 223
7.13 APPENDIX M: Parent Informed Consent form (Shona) 224
7.14 APPENDIX N: Assent forms for child participants..... 226
7.15 APPENDIX O: Assent forms for child participants (Shona)..... 227
7.16 APPENDIX P: Questionnaire on Demographics of the caregiver and the child 229
7.17 APPENDIX Q: Questionnaire on Demographics of the caregiver and the child (Shona).. 235
7.18 APPENDIX R: Test of Playfulness..... 243
7.19 APPENDIX S: Interview Guide 244
7.20 APPENDIX T: Delphi study Participant Information Statement..... 246
7.21 APPENDIX U: First Round Delphi Questionaire..... 250
7.22 APPENDIX W: Second Round Delphi Questionnaire..... 268

List of Figures

Figure 1.1: Model of Children's Play (Adapted from Cooper, 2000) 24
Figure 1.2: The UK MRC Framework by (Craig et al., 2008) 25
Figure 1.3: Structure of thesis 30
Figure 2.1: PRISMA Flow diagram 48
Figure 3.1: Mean outdoor and indoor scores by diagnosis 101
Figure 6.1: The UK MRC Framework (Craig et al., 2008) 160
Figure 6.2: Cooper's Model of children's play (Adapted from Cooper, 2000) 166
Figure 7.1: Model of children's play (adapted from Cooper, 2000) 206
Figure 7.2: Predicted impact of HIV/Aids on children's play 207

List of Tables

Table 2.1: Search strategy per literature base 43
Table 2.2: Articles rejected and the reasons 45
Table 2.3: Participants demographics and eligibility criteria 51
Table 2.4: Study aim, design, quality, outcome measures and outcomes 62
Table 2.5: Nuances of Play 76
Table 3.1: Demographics of the children 98
Table 3.2: Demographics of the responding caregiver 100
Table 3.3: Comparing indoor vs outdoor for ToP scores for HIV+ group sub-item analysis 103
Table 3.4: Mann Whitney U test comparing TD vs HIV + for indoors ToP scores item analysis 104
Table 3.5: Differences in elements of playfulness based on ToP item scores between TD and HIV+ 106
Table 3.6: Differences on ToP Social Skill item scores between TD and HIV+ 107
Table 4.1: Participants of the study 124
Table 4.2: Themes and categories 125
Table 5.1: Demographic details of experts 147
Table 5.2: Play-based intervention principles 149
Table 5.3: Techniques to be included in the Play-based Intervention Framework 150
Table 5.4: Topics to be included in the pre-intervention program 151

List of Abbreviations

ADHD	:	Attention Deficit Hyperactivity Disorder
ART	:	Antiretroviral Therapy
Aids	:	Acquired Immunity Deficiency Syndrome
CP	:	Cerebral Palsy
DCD	:	Developmental Coordination Disorder
DSM	:	Diagnostic and Statistical Manual of Mental Disorders -5
HIV	:	Human Immunodeficiency Virus
ICF	:	International Classification of Functioning, Disability and Health
JREC	:	Joint Research Ethic Committee
MRCZ	:	Medical Rehabilitation Council of Zimbabwe
NHMRC	:	National Health and Medical Research Council
PRISMA	:	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PICIHBI	:	Play Informed, Caregiver Implemented, Home based Intervention
RCT	:	Random Control Trial
SHCN	:	Special Health Care Needs
ToP	:	Test of playfulness
TOES	:	Test of Environmental Supportiveness
UK MRC	:	United Kingdom Medical Research Council
UNCRC	:	United Nations Convention on the Rights of the Child
WHODAS	:	World Health Organisation Disability Assessment Schedule
WFOT	:	World Federation of Occupational Therapists

Operational Definitions

1. *Play*: is '…a transaction with the environment that is intrinsically motivated, internally controlled and free from the constraints of reality and framed in the play transaction…' Skard & Bundy (2008 p. 71).

2. *Playfulness:* is the child's disposition to play and consists of four elements which are internal control, intrinsic motivation, freedom to suspend reality and framing (Hamm, 2006; Skard & Bundy, 2008).

3. *Typically developing playmate:* is defined as a child who has not been diagnosed with any chronic physical, mental and/or behavioural conditions and to whom no concerns had been raised about development by the caregiver or health professionals.

4. *Context:* is referred to as the systems that surround the child and affect the child's play as well as development. The systems include the micro-system, meso-system, exo-system and the macro-system (Bronfenbrenner, 1977). In occupational therapy the terms context and environment have been used interchangeably. According to Cooper (2000), the environment is referred to as the physical (play space, play material), social (presence of playmates, attitudes of people) and the cultural and family milieu (beliefs). Context in this study will also refer to all factors that impact society as a whole.

5. *Children with HIV/Aids:* in this study, the term children with HIV/Aids denotes children aged between 4 and 9 years, who have been diagnosed by a physician as being HIV-positive and are currently receiving antiretroviral therapy.

6. *Low resourced setting:* is a less developed area in terms of infrastructure such as electricity, transportation and buildings with limited access to material resources for the population. Additionally, there may be limited access to funds to cover healthcare and education costs as well as high levels of unemployment in the formal private and public sector.

7. *Occupation centred practice:* occurs when occupational therapy assessment, intervention and evaluation are based and focused on occupation (Rodger & Ziviani, 1999). In this study, the main occupation focused on is play involving children; thus assessment, intervention and evaluation is based on the play of the child in the context

where they live and learn. Play becomes the main goal/output of occupational therapy service.

8. *Play-based intervention:* are practices designed to improve the play or address other performance component difficulties in children through interactive play. During such intervention, the child leads the intervention process by deciding with whom, with what and how to play (Rodger & Ziviani, 1999).

9. *Theoretical frameworks:* consist of an interdisciplinary theoretical core made up of constructs derived from within the occupational therapy knowledge base as well as from scientific disciplines outside the profession (Ikiugu et al., 2009). These are used to guide decision making in practice.

1 CHAPTER 1: Introduction

1.1 Introduction

This chapter serves to situate the context, focus, and scope of this doctoral thesis aimed at developing a framework for a play-based intervention for children with Human Immune-deficiency Virus and Acquired Immunodeficiency Syndrome (HIV/Aids) living in a low resourced setting. The researcher's personal experiences which ignited curiosity for the study, as well as the context within which the study took place will be shared. This will be followed by the problem statement, research aim and specific questions which were pursued, highlighting the significance of the study. The chapter concludes by presenting a theoretical framework which guided the research process and outlining the overall structure of the thesis.

1.2 Background of the study

This doctoral study was undertaken following my interest to learn innovative and evidence based approaches in occupational therapy to contribute to the health and wellbeing of children with HIV/Aids living in low resourced settings. Having been born in a low resourced setting in Zimbabwe, I am well aware of the physical, social and cultural struggles one confronts to achieve what is otherwise ordinary human life aspirations. These daily struggles can be compounded by poverty and HIV/Aids, both of which are highly prevalent in many low resourced settings, such as Zimbabwe. HIV/Aids is also associated with stigma, which further limits participation in meaningful everyday occupations.

As an occupational therapist, I have always understood my role in relation to the ability to work with all people, including those living with HIV/Aids, in order to promote engagement and participation in everyday meaningful occupations (Schurgers et al., 2010). Unfortunately, occupational therapists were not involved in any HIV/Aids intervention at the hospital where I used to work on a rotational basis during years 2007 to 2011. Rarely would doctors refer an individual with HIV/Aids for occupational therapy services. This puzzled me and I started to think deeply on how occupational therapists could be more involved in contributing to the HIV programs at the hospital and the community I served.

A breakthrough in my desire to contribute in addressing health challenges faced by individuals with HIV/Aids occurred when I started to work on a paediatric hospital rotation during 2010. A physiotherapist and I used to run an outpatient clinic every Tuesday and caregivers/parents had to continue with therapy for their children at home through home-

based programs. The most common conditions we used to attend to at the clinic included cerebral palsy, developmental delays, Autism spectrum disorders and Down syndrome. Although there were very few such cases in 2010, I started to see children with HIV-related developmental delays and disabilities at the clinic. HIV-related developmental delays are disorders in children which occur as a result of the detrimental neurotropic effect of HIV on the developing brain. These disorders can cause learning difficulties, cerebral palsy, intellectual disabilities, delayed milestones and impact on the independence of the child in activities of daily living (Potterton, Cooper, Goldberg, Gajdosik and Baillieu, 2008). At that time not much research had been documented on occupational therapy management for children with HIV/Aids globally, let alone from low resourced settings. Compared to other children with other conditions such as cerebral palsy, who also attended the same clinic, working with children with HIV-related, developmental delays and their caregivers provided a unique experience. This reaffirmed my desire and conviction that occupational therapy had an important role to play in the health and wellness of people with HIV/Aids. But the question that continued to stand out for me was, how can occupational therapy effectively contribute to the health and wellness of this population, including children?

Experience at the paediatric clinic inspired my masters research project which mainly focused on understanding the perspectives of caregivers on caring for children with HIV related neurodevelopmental disabilities. Findings from that thesis revealed that caregivers could not share their role of caring for their child with others because they felt it was too much a burden to pass on to someone else. Of significant interest in that study was that caregivers valued their children engaging and participating in play. To them play was '*the magic'*, it was viewed as a sign for health and a yard stick to measure growth and development (Munambah, Gretschel, et al., 2020).

The findings from the study by Munambah, Gretschel, et al. (2020) revealed many aspects I had missed in previous years when I worked with children with HIV/Aids. In practice, focus was mainly on addressing performance components deficits (e.g., muscle tone, cognitive functioning, and endurance); play was just a medium to achieve other therapeutic goals and was rarely an outcome of therapy in and of itself. Having been introduced to concepts around human occupation during my master's degree, as well as experiences of working with children with HIV/Aids, it was clear to me that there is need to promote play in children with HIV/Aids. Research has also shown that children with HIV/Aids are at risk of developmental deficits, which are likely to impact participation in play (Ramugondo et al., 2018). However,

the question I felt still needed to be addressed was how and in what ways occupational therapists can promote the play of children with HIV/Aids, especially in a low resourced setting such as where I used to work.

Both my masters and further reading inspired me to want to understand the play of children with HIV/Aids and to explore how play could be used as a potential resource to promote health in this population. Play, like any other occupation, influences health and wellbeing and the benefits of play have been noted in research (Milteer & Ginsburg, 2012). Promoting play in children with HIV/Aids is regarded as integral to holistic occupation-based occupational therapy practice for these children (Lynch et al., 2018). However, there are no evidence-based guidelines for occupational therapists on promoting play in children with HIV/Aids, especially in low resourced settings. My doctoral thesis is therefore focused on developing a play-based intervention framework for children with HIV/Aids living in a low resourced setting, specifically, Zimbabwe.

1.3 The context of HIV/Aids in Zimbabwe

According to the Zimbabwe HIV Estimates report (2018), about 1.33 million people from a total population of 13 million are living with HIV/Aids and, of these, 5.8% (76,600) are children under the age of 15 years. Most infections in children are through mother to child or vertical transmission (Hilburn et al., 2010). In Zimbabwe, management of HIV/Aids is centred on awareness raising, screening for HIV, CD4 testing, Antiretroviral therapy (ART) initiation and counselling services (Duri et al., 2013). Occupational therapy services are not readily available to persons with HIV/Aids; they can only be assessed when an individual has been referred at the discretion of doctors.

Although the HIV infection rates have reduced due to a number of prevention interventions, such as the implementation of mother to child transmission prevention programs, there are still cases of children infected with HIV/Aids in Zimbabwe (Campbell et al., 2012). A study done in Zimbabwe revealed that approximately 9% of children with HIV/Aids are at risk of developing neurodevelopmental delays (Kandawasvika et al., 2011). Similarly another study at one of the outpatient clinics in Zimbabwe reported that a significant number of children with HIV/Aids had cognitive delays, language delays and motor delays (Hutchings & Potterton, 2014). Although, most of the deficits reported for children with HIV/Aids point to limitations in play, very few studies have reported on the specific play deficits of these children (Ramugondo et al., 2018).

The impact of HIV/Aids on children's play and development is also significantly affected by poverty. Most people affected by HIV/Aids have been reported to have a low socio-economic status (Duri et al., 2013). One of the major drivers of increase in HIV/Aids is unsafe sexual behaviours, which are precipitated by economic need and food insufficiency (Chevo & Bhatasara, 2012; Pascoe et al., 2015). In Zimbabwe, the situation is worsened by the socio-economic crisis the country is currently experiencing. This, in turn, has affected the occupations that adults and children engage in everyday life. In rural Zimbabwe, everyday activities of both children and adults are mainly centred on survival (Campbell et al., 2012). Economic factors that threaten survival, combined with cultural and relational practices, are likely to limit engagement and participations in meaningful occupations, such as play, for children.

1.4 Problem statement

With the need to intervene holistically when working with children with HIV/Aids, occupational therapists are often faced with challenges regarding how to promote play in low resourced countries. To add to this complexity, the conceptualisation and value of play may be different from how play is regarded in occupational therapy discourse dominated by scholars from well-resourced countries. Hammell and Iwama (2012) pointed out that most models and theories that inform practice have been developed in western countries. This could be problematic when applied to African contexts where there are different contextual challenges. Dender and Stagnitti (2015) noted that in most cases, occupational therapists are equipped with a Western theory base without culturally appropriate tools to promote play in context. Occupational therapists are increasingly becoming aware of the significance of culture and various ways in which cultural behaviours and beliefs shape everyday doing. Thus, there is a growing need to develop context-based models that promote play in children. To develop effective interventions, there is need to create new knowledge responsive to contexts within which the interventions will be delivered and how health problems, such as HIV/Aids, may intersect with these contextual factors. There is currently no published play-based intervention framework focused on promoting play in children with HIV/Aids, particularly in low resourced settings.

1.5 Research aim

The overall aim of the current research was to develop a framework for a play-based intervention for promoting the play for children living with HIV/Aids in a low resourced

setting. To address this aim, the research sought to conduct a systematic review to gather available evidence, explore and describe the play profiles of children with HIV/Aids living in a low resourced setting, and to provide a comparison of the similarities and differences in the level of playfulness in children with HIV/Aids compared to those without a known HIV/Aids diagnosis. Furthermore, the study provided an understanding of the context of play for children with HIV/Aids from caregivers' perspectives and gained consensus on the play-based intervention from experts.

1.6 Purpose of study

Interventions aimed at promoting play in context can be challenging when the therapist has to engage with caregivers who may hold different views about play from that of the therapist. The outcomes of this study aim to contribute to the understanding of play in children with HIV/Aids living in low resourced settings. Although play has been used by occupational therapists for a long time (Dender & Stagnitti, 2015), there is need to continuously review its conceptualisation and use in everyday practice to promote evidence-based practice. Occupational therapy has extended its focus from an individualistic to a broader focus of the environment that influences engagement and participation in occupations (Kuo, 2011). Thus, the conceptualisation of play ceases to be narrowly focussed on the child, but towards considerations of the environment and the possibilities of enabling play occupations in context. Findings from this study will help occupational therapists in low resourced settings, such as Zimbabwe, to develop an understanding of playfulness and play among children with and without HIV/Aids, which will enhance paediatric occupational therapy practice in those settings. At a national level in Zimbabwe, the findings are likely to provide a basis for advocacy work related to the allocation of resources, as well as broadening the scope of health services provision for children with HIV/Aids.

1.7 Significance of the study

Play is an integral component of child development and has been incorporated in Article 31 of the United Nations convention of the rights of children as a right. Furthermore, the World Federation of Occupational Therapists endorsed the United Nations UN declaration of human rights and states that every person has a right to engage in meaningful occupations (Therapists, 2006). The conceptualisation of play as an occupation makes it a right for every child (including those with HIV/Aids) to engage, participate and to experience despite his or

her limitations. Thus, this study approaches play from a human rights perspective by exploring how play for children with HIV/Aids is different from that of children without HIV/Aids, with the aim of developing guidelines for interventions to promote play in this population.

In Zimbabwe, various efforts have been put in place to reduce child mortality. Kuonza et al. (2010) reported how the introduction of Highly Active Antiretroviral Therapy (HAART) has reduced child mortality rates. As a result, there are more children surviving HIV infection or exposure. In tackling the Millennium Development Goal number four of reducing child mortality and goal number six aimed at combating the spread of HIV/Aids, the Government of Zimbabwe developed and implemented the national child survival strategy for Zimbabwe during the period of 2010 – 2015 (UNICEF, 2010). The national child survival strategy sets out to integrate maternal, new-born and child health services at all health institutions mainly focusing on reducing child mortality. The Millennium Development Goals were preceded by Sustainable Development Goals. Sustainable Development Goal 3 implores governments to promote the health and well-being of present and future generations, including children with HIV/Aids (Kharsany & Karim, 2016). The efforts of saving children's lives need to be complimented by availing opportunities for children to live meaningful lives. Play as an occupation supports health and wellbeing (Wilcock, 2006). Thus, play as a primary childhood occupation has potential to promote health in all children, especially those with HIV/Aids.

1.8 Theoretical Frameworks

Theoretical frameworks provide a useful foundation to understand the problem, predict the possible changes and provide workable ways of solving problems when designing complex interventions (Campbell et al., 2000). Several interventions used in occupational therapy have been criticised for lacking a theoretical framework which guide their development and implementation (Wilkes-Gillan et al., 2016). In occupational therapy, theoretical frameworks are used to guide decision making processes in practice and are helpful in explaining the domains within which one operates (Ikiugu et al., 2009). In this study an eclectic approach was adopted whereby two theoretical frameworks were applied to guide the development of a play-based intervention framework. The United Kingdom Medical Research Council (UK MRC) Framework for development and evaluations of complex interventions (Craig et al., 2013) and the model of children's play developed by Cooper (2000) will be used in this study. The two theoretical frameworks were chosen on the premise that the UK MRC

Framework for development and evaluations of complex interventions would guide the intervention development process and the model of children's play would provide some guidance on the content of the play-based intervention framework.

1.8.1 *Model of children's Play*

Cooper (2000) developed a model of children's play to critically examine the impact of child abuse on children's play, however, it can be applied to children with other forms of health problems and disabilities (Rodger & Ziviani, 1999). Cooper's Model of children's play was selected for use in this study as it provides an occupational perspective on how the play of children with disabilities is affected. The model also provides a lens through which the physical and environmental contexts can be explored, including how the cultural and familial milieu influence both the child's developmental skills and individual play styles (Stagnitti, 2003). The model is valuable for use by occupational therapists in broadening their understanding of the play of children and the contexts within which it occurs (see Figure 1.1)

> Cooper's Model of children's play is based on a widely accepted definition of play: "A transaction that occurs between the individual and their environment that is intrinsically motivated, internally controlled, free from the constraints of objective reality and requires skills related to framing (reading and responding to cues)" (Skard & Bundy, 2008, p. 71). This model of children's play considers how children's difficulties and the environment would impact on their play with peers. The model of children's play has three components: (1) The child's developmental capacities (cognitive, physical and social skills); (2) individual play style (internal control, freedom to suspend reality and intrinsic motivation) which makes up the child's contribution to play transaction; and (3) the environment and the cultural milieu which influences the child's play.

For a child to successfully engage in play, they have to have a certain level of cognitive, physical and social skills that underpin the child's play actions (Ramugondo et al., 2018). Conversely, restrictions in play are likely to affect development and maturation of these developmental skills (Rodger & Ziviani, 1999). The individual play styles are the elements of playfulness which have been described as the child's disposition to play (Bundy, 1997; Cooper, 2000). The child's physical and social environment includes physical play spaces, availability of play materials, and if other children or adults would be present (Cooper, 2000). The cultural and family milieu includes, but is not limited to, the socio-economic status,

cultural and ethnic beliefs, and parenting practices. The environment can either promote or restrict the play of the child (Rodger & Ziviani, 1999).

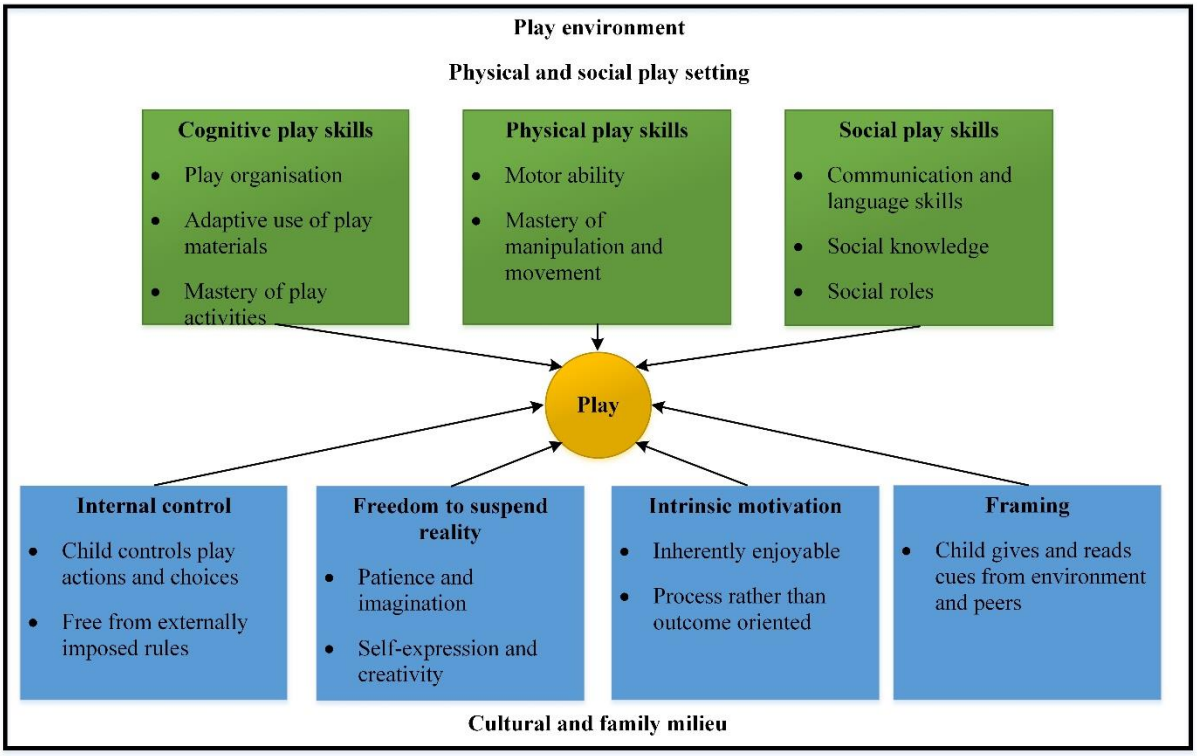


Figure 1.1: Model of Children's Play (Adapted from Cooper, 2000)

1.8.2 *The UK MRC Framework*

The UK MRC Framework for development and evaluations of complex interventions was used as the preferred guide to conceptualise the development of a play-based intervention framework for children with HIV/Aids in a low resourced setting, because the play-based intervention is complex. Complex interventions are described as '….those interventions with several interacting components, have practical and methodological difficulties and thus have difficulties in standardising design and delivery of intervention'(Craig et al., 2008, p. 2). Play-based interventions can be classified as complex because they are designed to target a broad range of play skills/behaviours and must take into account the many contextual factors that interplay when a child is playing (Henning et al., 2016).

The UK MRC Framework consists of four main phases. The first phase is the development phase, followed by feasibility and piloting (phase 2), the evaluation (phase 3), and implementation (phase 4). Figure 2.1 depicts the UK MRC Framework phases of developing and evaluating complex interventions. Although the framework emphasises using a phased

approach when developing and evaluating complex interventions, the content and purpose of the phases have been used differently across various research examples (Murchie et al., 2007). Despite the phases diagrammatically presented as uni-directional, they follow an iterative process.

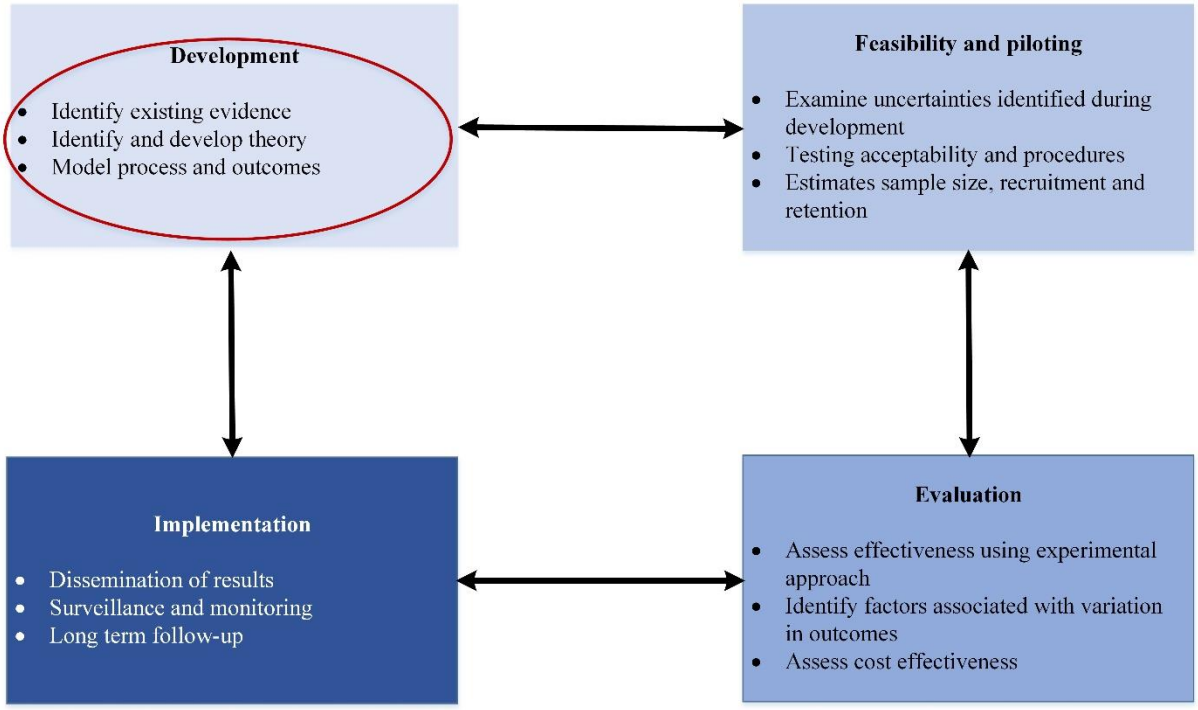


Figure 1.2: The UK MRC Framework by (Craig et al., 2008)

This doctoral thesis is focused mainly on the development phase, which includes identifying existing evidence, gathering further data, and selecting an applicable theoretical framework for a play-based intervention for children with HIV/Aids in a low resourced setting.

1.8.2.1 Identifying the evidence base

According to the UK MRC Framework (Craig et al., 2008), the first step in developing a play-based intervention is to identify the evidence base. A broad range of literature was explored in the current study with the aim of identifying the relevant evidence base for developing a play-based intervention for children with HIV/Aids. A review of literature revealed that two systematic reviews on play-based interventions for children with ASD had been carried out (Kent, Cordier, Joosten, Wilkes-Gillan, Bundy, et al., 2020; Kossyvaki & Papoudi, 2016). In most research, play outcomes are rarely the focus of play-based intervention, instead underlying skills such as communication and physical or social skills are explored. Due to paucity of literature on play-based interventions for children with HIV/Aids

that focused on play and directly on the child, the search for evidence was broadened in order to encompass all conditions classified as children with special health-care needs (SHCN). Children with SHCN have been described as "children who have or are at risk for a chronic physical, developmental, behavioural, or emotional condition, and who also require health and related services of a type or amount beyond that required by children generally" (McPherson et al., 1998, p. 138). Furthermore, to get a full picture of the participation gaps a play-based intervention should focus on the review specifically focussed on comparing the similarities and differences in play for children with SHCN. Thus a systematic review comparing the play profiles of children with SHCN with typically developing children was conducted.

A systematic review on comparing the play profiles of children with SHCN with typically developing children was conducted because an initial search by the researcher did not yield any study that had focused on play-based intervention for children with HIV/Aids. The only work that could be found in that earlier search was on caregivers and their children with HIV/Aids conducted in South Africa (Ramugondo, 2004). Building on this, Ramugondo and her students developed a play-informed, caregiver-implemented home-based intervention aimed at promoting development, self-care, play and playfulness in children with HIV/Aids, as well as caregiver efficacy (Meissner, 2016; Otto, 2016; Uys, 2016). Even though one aspect of the broader research project was focused on play and playfulness, the intervention was not targeted directly at the play of the child, but the caregivers, sharing skills with them that they could use at home to promote play in their children (Ramugondo et al., 2018).

Research questions addressed in the systematic review presented in chapter 2 of this thesis are as follows:

1) Is the overall play profile of children with SHCN similar or different to that of typically developing children?
2) Is the play duration of children with SHCN similar or different to that of typically developing children?
3) Are the types and/or forms of play of children with SHCN similar or different to that of typically developing children?
4) Are the play behaviours of children with SHCN similar or different to that of typically developing children?

1.8.3 *Gathering further data*

When developing a complex intervention, it is important to develop a theoretical understanding of the likely process of change by drawing on existing evidence and theory, supplemented and enhanced, if necessary, by empirical research (Craig et al., 2013). Given the limited literature on play-based interventions for children with HIV/Aids, there was a need to generate evidence to inform the intervention. Thus, primary data which included profiling the play of children with HIV/Aids through observing the children playing with a playmate was collected. We also interviewed the caregivers to gain their perspectives on their children's play. The purpose of gathering evidence from primary sources was also to identify possible deficits and how these could be potentially addressed through an intervention (Craig et al., 2008).

1.8.3.1 Play profiles of children with HIV/Aids

Despite HIV/Aids being first diagnosed two decades ago, very few research studies have tried to explore and understand the play of children with HIV/Aids from an occupational therapy perspective. Examples of research in occupational therapy done on play include studies conducted among children with various conditions such as autism spectrum disorders (Dominguez et al., 2006; Kuhaneck et al., 2020), ADHD (Cordier et al., 2010a), cerebral palsy (Blanche, 2008), and foetal alcohol syndrome (Pearton et al., 2014). Most research has explored the benefits of play (Halfon & Newacheck, 2019), however, the specific play process in treatment remained unexplored, especially in low resourced settings.

Although the study by Bartie et al. (2016) explored the play experiences of children in a low resourced setting and generated valuable information to inform practice, the study focused on play for typically developing children. There is a paucity of studies that have explored play profiles of children with HIV/Aids, particularly in low resourced settings (Ramugondo et al., 2018), whose play is likely to be affected in various ways due to cognitive factors, such as executive functioning deficits, and contextual factors such as stigma associated with HIV/Aids. The researcher thus sought to understand in a nuanced way how the play of children with HIV/Aids may be affected. This knowledge could be used to determine which mechanisms of change (techniques and approaches) are best applied to offset the play deficits. In this study, the play profiles of children with HIV/Aids were compared against play profiles of age and gender matched typically developing children. Each child with

HIV/Aids was observed playing with his/her playmate at the clinic/school and at their homes, thus, in their natural setting. Detail of the comparative study on play profiles of children with HIV/Aids is presented in chapter 3 of this thesis and the following research questions were answered:

a) What are the differences in overall play profiles of children with HIV/AIDS compared to typically developing children?
b) How are the play profiles (indoor versus outdoor) of children with HIV/Aids similar or different to typically developing children?
c) Is there a difference in individual item scores of ToP categories between children with HIV compared to typically developing children?

1.8.3.2 Caregivers' perspectives on play of children with HIV/Aids

The conceptualisation of play as an occupation makes it important to understand play in context. Play as an occupation occurs as a transaction between the child and their context (Kuo, 2011). Thus, apart from understanding the play of children with HIV/Aids through observations of the children playing, it is important to also explore and understand the context in which play happens. Hence, the researcher undertook a qualitative study to understand play from the caregivers' perspectives. Caregivers spend more time with their children than health professionals, thus they provide important insights through which to explore and understand play, as well as identifying areas that need intervention and possible ways of promoting play in children with HIV/Aids in their own contexts. Caregivers highlighted areas of concern and details about their children which are presented in chapter 4 of this thesis.

The following research questions were addressed:

a) What are the perspectives of caregivers on the play of children with HIV/Aids living in a low resourced setting?
b) What factors influence engagement and participation in play for children with HIV/Aids living in a low resourced setting?
c) What can be done to promote the play of children with HIV/Aids?

1.8.4 *Identifying and developing an appropriate theoretical framework*

Identifying and/or developing an applicable theoretical framework can provide an essential basis upon which to design an intervention (Craig et al., 2013). In this study, evidence from literature was synthesised by means of a systematic review. This was followed by comparative study on the play profiles of children with HIV/Aids. Thereafter, perspectives of caregivers on the play of their children with HIV/Aids were gained through in-depth interviews. Based on the integration of findings from these various aspects to the study, expert opinions were sought through a Delphi approach. Consensus was reached through the Delphi Study on the theoretical framework to guide the play-based intervention, principles of the intervention and active ingredients to be included in the intervention. Details about the Delphi Study are presented in chapter 5 of this thesis. The main purpose of the Delphi was to develop a framework for a play-based intervention for children with HIV/Aids in low resourced settings.

The research questions for the Delphi study were:

1) What is the theoretical framework applicable to the development of a play-based intervention for promoting play of children with HIV/Aids living in low resourced settings?
2) What treatment principles should be included in the play-based intervention for promoting play of children with HIV/Aids?
3) What active ingredients/techniques should be included in the play-based intervention for promoting play of children with HIV/Aids?

1.9 Thesis Outline

The thesis is presented in six chapters as shown in Figure 1.3 below. The first chapter (Introduction) and the last chapter (chapter 6 - Discussion and conclusion) are traditional chapters of a thesis. All the other chapters (2-5) are journal manuscripts which either have been published or are currently under review at international peer reviewed journals. Each chapter was designed to serve a purpose in answering the set research questions of the respective studies. Thus, chapter 1 introduces the reader to the study by first presenting the researcher's personal motivation and background of the study. The problem statement, research aim(s) and significance of the study is also stated. Chapter 2 is a systematic review comparing the play profiles of children with SHCNs with typically developing children.

Chapter 3 presents a published journal manuscript based on a cross sectional comparative study on the play profiles of children with HIV/Aids. Chapter 4 is a qualitative study exploring the play of children with HIV/Aids from the caregivers' perspectives. Chapter 5 presents a Delphi study conducted to gain consensus from experts on the play-based intervention framework for promoting play in children with HIV/Aids living in a low resourced setting.

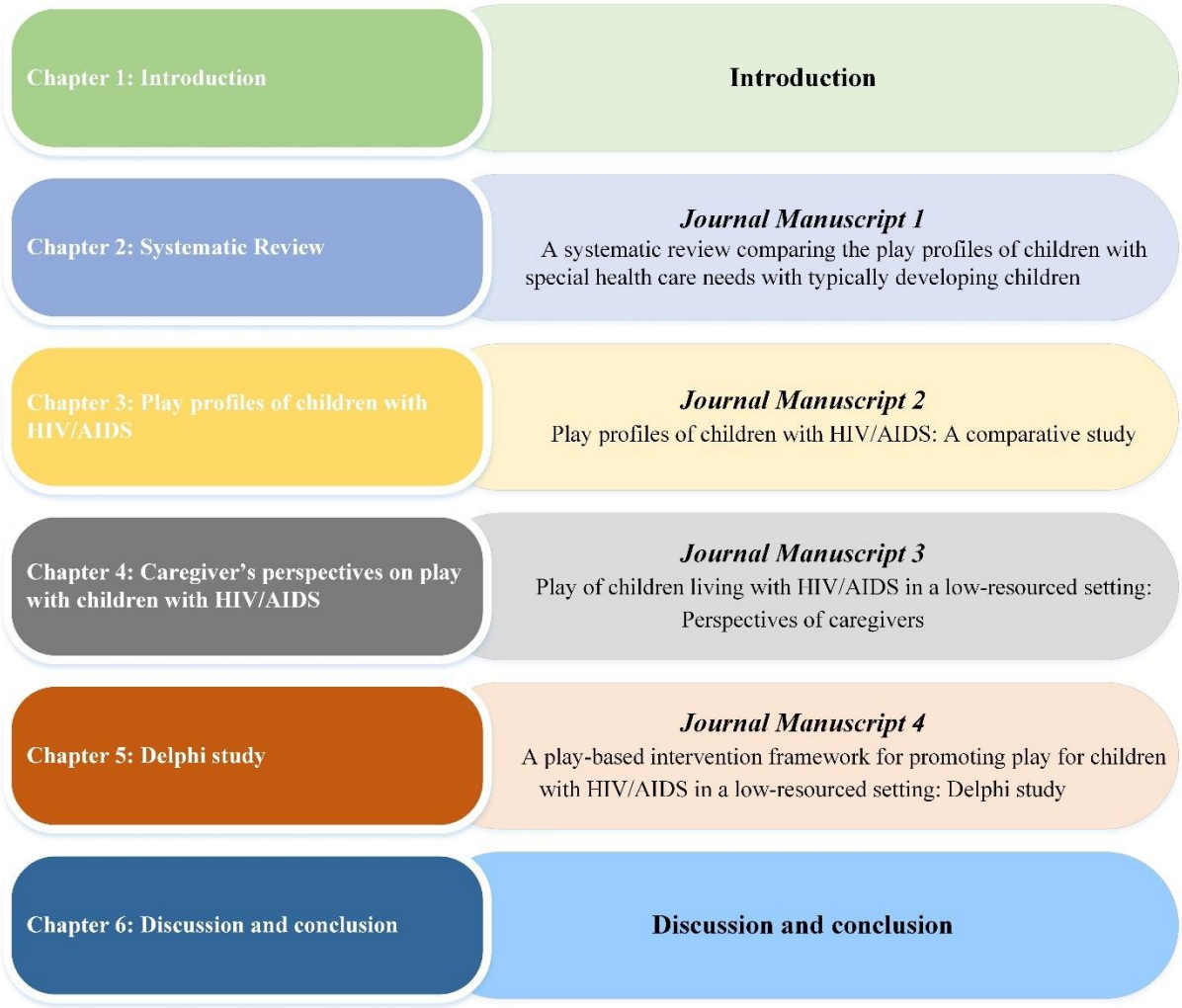


Figure 1.3: Structure of thesis

1.10 Conclusion

This chapter introduced the research study aimed at developing a play-based intervention for children with HIV/Aids living in a low resourced setting. The paucity of occupational therapy research on the play for children with HIV/Aids, especially from low resourced settings, coupled with the researcher's experience was the motivation for carrying out this study. The process of developing a play-based intervention was guided by the UK MRC Framework for

development and evaluation of complex intervention and Cooper's Model of children's play. The following chapters report on the systematic process which was undertaken to develop the intervention framework and concludes with a presentation of the proposed play-based intervention framework for children with HIV/Aids living in a low resourced setting.

1.11 References

1) Bartie, M., Dunnell, A., Kaplan, J., Oosthuizen, D., Smit, D., van Dyk, A., . . . Duvenage, M. (2016). The Play Experiences of Preschool Children from a Low-socio-economic Rural Community in Worcester, South Africa. *Occupational Therapy International, 23*(2), 91-102.
2) Blanche, E. I. (2008). Play in children with cerebral palsy: Doing with-not doing to. *Play in occupational therapy for children*, 375-393.
3) Bundy, A. (1997). Play and playfulness: What to look for. *Play in occupational therapy for children*, 52-66.
4) Campbell, C., Skovdal, M., Mupambireyi, Z., Madanhire, C., Robertson, L., Nyamukapa, C. A., & Gregson, S. (2012). Can AIDS stigma be reduced to poverty stigma? Exploring Zimbabwean children's representations of poverty and AIDS. *Child: care, health and development, 38*(5), 732-742. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3437489/pdf/cch0038-0732.pdf
5) Campbell, M., Fitzpatrick, R., Haines, A., Kinmonth, A. L., Sandercock, P., Spiegelhalter, D., & Tyrer, P. (2000). Framework for design and evaluation of complex interventions to improve health. *bmj, 321*(7262), 694-696.
6) Care, M. o. H. a. C. (2018). *Zimbabwe National and Sub-national HIV Estimates report 2017*. Government Printers
7) Chevo, T., & Bhatasara, S. (2012). HIV and AIDS Programmes in Zimbabwe: Implications for the Health System. *ISRN Immunology, 2012*, 609128. doi:10.5402/2012/609128
8) Cooper, R. J. (2000). The impact of child abuse on children's play: A conceptual model. *Occupational Therapy International, 7*(4), 259-276.
9) Cordier, R., Bundy, A., Hocking, C., & Einfeld, S. (2010). Comparison of the play of children with attention deficit hyperactivity disorder by subtypes. *Australian occupational therapy journal, 57*(2), 137-145.
10) Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2008). Developing and evaluating complex interventions: the new Medical Research Council guidance. *bmj, 337*.
11) Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2011). Developing and evaluating complex interventions. *Medical Research Council, UK*.
12) Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2013). Developing and evaluating complex interventions: the new Medical Research Council guidance.
13) Dender, A. M., & Stagnitti, K. (2015). Children's play in the Australian Indigenous context: the need for a contemporary view. *International Journal of Play, 4*(1), 3-16.
14) Dominguez, A., Ziviani, J., & Rodger, S. (2006). Play behaviours and play object preferences of young children with autistic disorder in a clinical play environment. *Autism, 10*(1), 53-69.
15) Duri, K., Stray-Pedersen, B., & Muller, F. (2013). HIV/AIDS: The Zimbabwean situation and trends.
16) Gerlach, A., Browne, A., & Suto, M. (2014). A critical reframing of play in relation to Indigenous children in Canada. *Journal of Occupational Science, 21*(3), 243-258.

17) Hammell, K. R. W., & Iwama, M. K. (2012). Well-being and occupational rights: An imperative for critical occupational therapy. *Scandinavian journal of occupational therapy, 19*(5), 385-394.
18) Henning, B., Cordier, R., Wilkes-Gillan, S., & Falkmer, T. (2016). A pilot play-based intervention to improve the social play interactions of children with autism spectrum disorder and their typically developing playmates. *Australian occupational therapy journal, 63*(4), 223-232.
19) Hilburn, N., Potterton, J., & Stewart, A. (2010). Paediatric HIV encephalopathy in sub-Saharan Africa. *Physical Therapy Reviews, 15*(5), 410-417.
20) Hutchings, J., & Potterton, J. (2014). Developmental delay in HIV-exposed infants in Harare, Zimbabwe. *Vulnerable Children and Youth Studies, 9*(1), 43-55.
21) Ikiugu, M. N., Smallfield, S., & Condit, C. (2009). A framework for combining theoretical conceptual practice models in occupational therapy practice. *Canadian journal of occupational therapy, 76*(3), 162-170.
22) Kandawasvika, G. Q., Ogundipe, E., Gumbo, F. Z., Kurewa, E. N., Mapingure, M. P., & Stray-Pedersen, B. (2011). Neurodevelopmental impairment among infants born to mothers infected with human immunodeficiency virus and uninfected mothers from three peri-urban primary care clinics in Harare, Zimbabwe. *Developmental Medicine & Child Neurology, 53*(11), 1046-1052.
23) Kent, C., Cordier, R., Joosten, A., Wilkes-Gillan, S., Bundy, A., & Speyer, R. (2020). A Systematic Review and Meta-analysis of Interventions to Improve Play Skills in Children with Autism Spectrum Disorder. *Review Journal of Autism and Developmental Disorders*. doi:10.1007/s40489-019-00181-y
24) Kharsany, A. B. M., & Karim, Q. A. (2016). HIV infection and AIDS in sub-Saharan Africa: current status, challenges and opportunities. *The open AIDS journal, 10*, 34.
25) Kossyvaki, L., & Papoudi, D. (2016). A Review of Play Interventions for Children with Autism at School. *International Journal of Disability, Development and Education, 63*(1), 45-63. doi:10.1080/1034912x.2015.1111303
26) Kuhaneck, H., Spitzer, S. L., & Bodison, S. C. (2020). A Systematic Review of Interventions to Improve the Occupation of Play in Children With Autism. *OTJR: Occupation, Participation and Health, 40*(2), 83-98.
27) Kuo, A. (2011). A transactional view: Occupation as a means to create experiences that matter. *Journal of Occupational Science, 18*(2), 131-138.
28) Kuonza, L. R., Tshuma, C. D., Shambira, G. N., & Tshimanga, M. (2010). Non-adherence to the single dose nevirapine regimen for the prevention of mother-to-child transmission of HIV in Bindura town, Zimbabwe: a cross-sectional analytic study. *BMC Public Health, 10*(1), 218.
29) Lynch, H., & Moore, A. (2016). Play as an occupation in occupational therapy. In: SAGE Publications Sage UK: London, England.
30) Meissner, R. J., Ferguson, J., Otto, C., Gretschel, P., & Ramugondo, E. (2017). A play-informed, caregiver-implemented, home-based intervention for HIV-positive children and their families living in low-income conditions in South Africa. *World Federation of Occupational Therapists Bulletin, 73*(2), 83-87.
31) Milteer, R. M., Ginsburg, K. R., & Mulligan, D. A. (2012). The importance of play in promoting healthy child development and maintaining strong parent-child bond: Focus on children in poverty. *Pediatrics, 129*(1), e204-e213.

32) Ministry of, H., & Child, C. (2010). National child survival strategy for Zimbabwe 2010–2015. In: MoHCC Harare.
33) Munambah, N., Gretschell, P., & Sonday, A. (2020). Being a mother of a child with HIV-related Neurodevelopmental Disorders in the Zimbabwean Context. *South African Journal of Occupational Therapy, 50*(1), 35-40.
34) Murchie, P., Hannaford, P. C., Wyke, S., Nicolson, M. C., & Campbell, N. C. (2007). Designing an integrated follow-up programme for people treated for cutaneous malignant melanoma: a practical application of the MRC framework for the design and evaluation of complex interventions to improve health. *Family practice, 24*(3), 283-292.
35) Otto, C. (2016). The impact of play-informed caregiver-implemented home-based intervention on the academic learning outcomes for HIV positive children (aged 5 years to 8 years) on Antiretroviral Therapy (ART) living in low income conditions: a randomized control trial.
36) Pascoe, S. J. S., Langhaug, L. F., Mavhu, W., Hargreaves, J., Jaffar, S., Hayes, R., & Cowan, F. M. (2015). Poverty, food insufficiency and HIV infection and sexual behaviour among young rural Zimbabwean women. *PloS one, 10*(1), e0115290.
37) Pearton, J. L., Ramugondo, E., Cloete, L., & Cordier, R. (2014). Playfulness and prenatal alcohol exposure: a comparative study. *Aust Occup Ther J, 61*(4), 259-267. doi:10.1111/1440-1630.12118
38) Ramugondo, E. (2004). Play and playfulness: Children living with HIV/AIDS. *Transformation through occupation*, 171-185.
39) Ramugondo, E., Ferreira, A., Chung, D., & Cordier, R. (2018a). A feasibility RCT evaluating a play-informed, caregiver-implemented, home-based intervention to improve the play of children who are HIV positive. *Occupational Therapy International, 2018*.
40) Ramugondo, E., Ferreira, A., Chung, D., & Cordier, R. (2018b). A Feasibility RCT Evaluating a Play-Informed, Caregiver-Implemented, Home-Based Intervention to Improve the Play of Children Who Are HIV Positive. *Occup Ther Int, 2018*, 3652529. doi:10.1155/2018/3652529
41) Rodger, S., & Ziviani, J. (1999). Play-based occupational therapy. *International Journal of Disability, Development and Education, 46*(3), 337-365.
42) Schurgers, J., Sinyangwe, S., Burger, S., Van Nieuwkerk, J., & Kamanga, E. (2010). Giving Children with HIV and AIDS a Future; The need for occupational therapy of HIV-positive children with developmental delay. *Medical Journal of Zambia, 37*(2), 93-98.
43) Skard, G., & Bundy, A. C. (2008). Test of Playfulness. In *Play in occupational therapy for children* (pp. 71-93).
44) Stagnitti, K. (2003). A review of play and play assessment used in occupational therapy. *Journal of Japanese association of occupational therapists, 22*(3), 267-280.
45) Uys, A. (2016). A randomized control trial investigating the effects of a play-informed care-giver implemented home-based intervention on playfulness for HIV positive children aged 10 months to 8 years on HAART from a low socio-economic status.
46) Wilcock, A. A. (2006). *An occupational perspective of health*: Slack Incorporated.
47) Wilkes-Gillan, S., Bundy, A., Cordier, R., Lincoln, M., & Chen, Y.-W. (2016). A randomised controlled trial of a play-based intervention to improve the social play

skills of children with attention deficit hyperactivity disorder (ADHD). *PloS one, 11*(8), e0160558.
48) World Federation of Occupational, T. (2006). Position statement on human rights. In: WFOT Londres.

2 CHAPTER 2: Systematic review

2.1 Introduction

This chapter presents a systematic review that was carried out to identify the evidence on the play of children with Special Health Care Needs (SHCN). The UK MRC Framework recommends that a systematic review be carried out to identify existing gaps, and develop a rationale for the intervention (Skivington et al., 2018). The systematic review compared the play profiles of children with SHCN with typically developing children. As mentioned in chapter 1, given the paucity of research on the play of children with HIV/Aids, the researcher decided to broaden the target population to include all children with SHCN despite this study focussing on children with HIV/Aids. The nuances of play of children with SHCN were discussed. The systematic review also described the study designs, populations included, play outcome measures utilised and findings of each study. A critical appraisal of the quality of study methodologies was reported on all studies included in the systematic review.

This chapter was accepted for publication in the Bio Med Research International Journal on 13 October 2020. It is published as:

> Munambah, N., Cordier, R., Speyer, R., Toto, S., & Ramugondo, E. L. (2020) A Systematic Review Comparing the Play Profiles of Children with Special Health Care Needs with Typically Developing Children. *BioMed Research International*, Article ID 9582795, 1-10. doi: 10.1155/2020/9582795

The article is presented as Microsoft Word document and has been formatted according to the BioMed Research International guidelines. A list of references for this chapter is presented at the end of the chapter.

2.2 Background Information

Generally, there is an increase in children with Special Health Care Needs (SHCN) worldwide (Mattson & Kuo, 2019), consequently, more focus has been on improving services to this population (Sannicandro et al., 2017). Some of the commonly identified health care conditions among children include ADHD, asthma, learning disability and cerebral palsy (Miller et al., 2018). Children with special healthcare needs have been defined as "children who have or are at risk for a chronic physical, developmental, behavioural, or emotional condition, and who also require health and related services of a type or amount beyond that required by children generally" (McPherson et al., 1998, p. 138). There has been challenges in coming up with a definition that is all encompassing for children with special healthcare needs (L. Huang et al., 2020). A systematic review by Van Der Lee et al. (2007) revealed that there is diversity in the concepts and approaches used to define children with healthcare needs. Some of the approaches used include (i) listing of conditions presumed to be chronic in nature, (ii) those children with conditions that tend to result in disability, and lastly (iii) children with conditions that result in more utilisation of health care services (Beers et al., 2016). Although there are various ways of defining children with SHCN, the above definition was selected for the current systematic review because it is more inclusive and captures the potential service needs of these children as compared to other definitions used in literature to capture the different types of health conditions and related participation limitations (Li Huang et al., 2020).

Despite the great variability in terms of the types and severity of special healthcare needs, children with SHCN experience multiple health conditions, poorer reported health status and reduced physical activity among other challenges (Li Huang et al., 2020). Children with SHCN are at risk of mental and behavioural problems, frequent readmissions to hospital, absence from school and limited capacity to engage in play (Van Dyck et al., 2004). Thus, children with SHCN are likely to experience challenges in their development and some of the common problems they experience include difficulty in learning and paying attention (Miller et al., 2018). As such, children with special healthcare needs are at greater risk than their healthy peers of experiencing adverse learning and developmental outcomes both in the short and longer term. All these adverse outcomes point towards the need for early intervention to minimise the impact of the condition. For children, play is commonly the medium for intervention delivery and an important therapeutic outcome in and of itself (Cordier et al., 2010a).

Play-based interventions are part of the several approaches that have been utilised by healthcare professionals to address deficits experienced by children with SHCN (Sterman et al., 2016). Play has been used in therapy for a long time, as either a means to address deficits or promoted as an end goal. Through play, children learn survival skills, develop resilience to deal with life events and all skills that are essential for transitioning into adulthood (Lynch & Moore, 2016). Play is also an important resource for learning and developing critical motor, cognitive and socio-emotional skills (Cordier et al., 2010a). Furthermore, play provides a natural context to explore behavioural and social difficulties, in addition to addressing interactional problems that affect children (Cordier et al., 2010a).

Even though play has been used as both a medium for intervention and a therapeutic agent for a very long time (Cordier et al., 2010a), as a multi-faceted phenomenon the construct remains elusive to define, given the dynamic and constantly evolving nature of the construct. A study by Ramugondo (2012) revealed how play progressed and changed from one generation to the next. The study highlighted the importance of context in shaping play. The context in terms of who plays with the child, availability of play things (Venkatesan, 2014) and play spaces, as well as culture influences the play of children. As children grow and develop more complex forms of play, they tend to develop certain gender preferences in selection of toys as facilitated through their context (Todd et al., 2018). Play is also shaped by culture (Vandenberg & Kielhofner, 1982), hence, the types and forms of play may vary from one culture to the next. A study by Berinstein and Magalhaes (2009) reported that "…play of children in Tanzania was different from the western perspective of play" in that their play was characterised by little or no involvement of adults in actual play and the children had a way of mixing play with work. As a result, the complexity, diversity and constantly changing nature of play make measuring play ability difficult for educators, clinicians, and researchers (Kent, Cordier, Joosten, Wilkes-Gillan, Bundy, et al., 2020).

The conceptualisation of play has been drawn from many disciplines to describe play at different stages, with implications for both assessment and practice (Kent, Cordier, Joosten, Wilkes-Gillan, Bundy, et al., 2020). Although there is some disagreement about the exact characteristics that comprise play; play is commonly defined by the characteristics that separate it from non-play (Pearton et al., 2014). For the purposes of this systematic review, play is defined as: "...a transaction between the individual and the environment that is intrinsically motivated, internally controlled, and free of many of the constraints of objective reality and skills related to framing (giving and responding to cues)" (Bundy et al., 2001, p.

227). Rather than viewing play in general terms, this review also includes studies that have focused on playfulness. Playfulness is a key aspect of play to explore in children with impairments, as it focuses on the quality of play and the adaptability and coping mechanisms of a child, regardless of ability. Playfulness is defined as a child's disposition to play, which remains constant over time and relates to a child's ability to cope in later life (Skard & Bundy, 2008). The construct of playfulness is characterised by four elements which are intrinsic motivation, internal control, freedom to suspend reality and framing (Skard & Bundy, 2008). Although play refers to the 'doing' of play, playfulness points to the very 'being' of play (Pearton et al., 2014). The process of promoting play in children extends beyond teaching play skills or practising play activities in therapy clinics. It includes rather, the design of context-focused interventions that focus on play, playfulness and participation in play by collating a detailed profile of all aspects of play in children (Barnes et al., 2017). A detailed play profile, in turn, is important in understanding children's play deficits and helps in formulating evidence-informed interventions (Halfon, 2017). The terms play, playfulness, play profiles and play behaviours have been used to denote play or various forms of play in literature. For the purpose of this study, the term play profiles will be used henceforth where appropriate.

Despite play being spontaneous, children with SHCN, including those children with ADHD (Cordier et al., 2010a), are likely to experience difficulties in engaging and participating in play. Restrictions to being able to play well with others can lead to children developing negative self-efficacy and becoming socially isolated (Barnes et al., 2017; Pearton et al., 2014) which, in turn, may result in further psychological sequelae later in life. Play is the window through which a child's development can be viewed, and by exploring their play profiles, we can develop a clearer picture of how other areas of development may be affected. An understanding of the play profiles of children with SHCN would be important in developing appropriate and evidence-based interventions for this population. However, there is paucity of high level evidence on the impact of SHCN on children's play (Miller & Kuhaneck, 2008; Wijlaars et al., 2016). High level evidence is needed to inform therapy needs and making evidence informed choices about the quality of interventions offered to children with special healthcare needs. Systematic reviews provide high level evidence by synthesising information from all accessible studies (Liberati et al., 2009), which can be used to guide practice and support development of appropriate strategies to improve play in children with SHCN. This systematic review aims to examine how the play profiles of

children with SHCN, is similar or different to that of typically developing children. The systematic review addressed the following research questions:

1) Is the overall play profile of children with SHCN similar or different to that of typically developing children?
2) Is the play duration of children with SHCN similar or different to that of typically developing children?
3) Are the types and/or forms of play of children with SHCN similar or different to that of typically developing children?
4) Are the play behaviours of children with SHCN similar or different to that of typically developing children?

2.3 Materials and Methods

PRISMA was used to guide the methodology and transparent reporting of this systematic review (Moher et al., 2009). The PRISMA checklist describes aspects of research that are deemed essential for the transparent reporting of systematic reviews. This systematic review is registered with PROSPERO International Prospective Register of Systematic Reviews (ID 2017: CRD42017072269). The systematic review addresses the research question, how is the play of children with SHCN similar or different to that of typically developing children?

Selection Criteria: Since play varies across the age groups, and the type and nature of play changes as the child matures (Cordier 2009), the study population has been limited to only include children aged 11 years and below. Also the selected children should have either: 1) a specified SHCN such as HIV/AIDS, chronic respiratory conditions, cancer, physical disabilities, such as cerebral palsy, spina bifida; and 2) behavioural and/or emotional disorders which are defined as disruptive impulsive conduct disorders and anxiety disorders according to the DSM 5. However, autism spectrum disorders were excluded from this study as a systematic review on play-based interventions for children with ASD was conducted by Kent, Cordier, Joosten, Wilkes-Gillan, Bundy, et al. (2020) and a review of play interventions for children with autism at school was carried out by Kossyvaki and Papoudi (2016).

The inclusion criteria for the studies were as follows:

- The studies could be of any design provided play was compared between two groups of children;

- At least one of the comparison groups should be children diagnosed with specified special healthcare needs; compared against typically developing children;
- At least one of the outcome measures should be play; and
- Articles were published in English and in peer reviewed journals.

The Exclusion Criteria were as follows:

- Studies that focussed on caregivers and/or siblings of participants who meet eligibility criteria;
- Data from presentations, conference proceedings, dissertations and thesis;
- Studies that reported on a play-based intervention but did not measure play as an outcome;
- Studies that investigated play in which video games and robotics are used. Play involving video games and robotics is structured and may not provide similar opportunities for social interaction, freedom to suspend reality and framing, and restricts the children to being creative outside the confines of the game/robotics. Moreover, as we were interested in understanding the play profiles of children with SHCN, the play context (naturalistic) needed to be consistent to allow for comparison across different population groups.
- Studies that used a psycho-analytical approach to play or so called 'play-therapy' approaches. According to Cattanach (2004), play therapy is a way of helping troubled children cope with their distress, using play as the medium of communication between the child and the therapist. Thus, play therapy is not an intervention aimed at addressing play deficits per se, but is mainly focussed on addressing emotional distress.

Information Sources and Search: A systematic literature search was conducted across the following five databases: CINAHL, Embase, ERIC, PsycINFO, and PubMed. The searches were done between 22 September and 10 December 2018. Additionally, reference lists of included studies were searched by hand to ensure that all appropriate articles were included in the review. All search strategies per database are presented in Table 1.

Data extraction (selection and coding): Through consultations with an expert panel experienced in play research and/or measurement development, a data extraction form was developed based on the review question. Variables sought from the checklist included: study

setting, study population, participant demographics, diagnosis of participants, play/playfulness outcome measures used, and the methodological quality of the included studies. Data on the methodological quality of the studies were extracted and scored independently by reviewers who were not authors of any of the studies included in the review. Authors of the included studies were contacted if additional information was needed to answer questions with regard to eligibility.

Table 2.1: Search strategy per literature base

Database	Subject Headings	Number of records
CINAHL	((MH "Intellectual Disability") OR (MH "Learning Disorders") OR (MH "Motor Skills Disorders") OR (MH "Movement Disorders") OR (MH "Apraxia, Developmental") OR (MH "Brain Injuries") OR (MH "Cerebral Palsy") OR (MH "Hydrocephalus") OR (MH "Fragile X Syndrome") OR (MH "Down Syndrome") OR (MH "Attention Deficit Hyperactivity Disorder") OR (MH "Fetal Alcohol Syndrome") OR (MH "Social Behavior Disorders") OR (MH "Affective Disorders") OR (MH "Child Behavior Disorders") OR (MH "Developmental Disabilities") OR (MH "Learning Disorders")) AND ((MH "Play Therapy") OR (MH "Play and Playthings") OR (MH "Play Therapy (Iowa NIC)") OR (MH "Play Participation (Iowa NOC)") OR (MH "Role Playing"))	675
Embase	(intellectual impairment/ OR mental deficiency/ OR motor dysfunction/ OR developmental coordination disorder/ OR tic/ OR apraxia/ OR traumatic brain injury/ OR cerebral palsy/ OR hydrocephalus/ OR fragile X syndrome/ OR Down syndrome/ OR attention deficit disorder/ OR fetal alcohol syndrome/ OR emotional disorder/ OR conduct disorder/ OR oppositional defiant disorder/ OR behavior disorder/ OR developmental disorder/ OR behavior disorder/ OR learning disorder/ OR hyperkinesia/ OR antisocial personality disorder/) AND (play/ OR play therapy/)	794
ERIC	(MAINSUBJECT.EXACT("Intellectual Disability") OR MAINSUBJECT.EXACT("Severe Intellectual Disability") OR MAINSUBJECT.EXACT("Moderate Intellectual Disability") OR MAINSUBJECT.EXACT("Mild Intellectual Disability") OR MAINSUBJECT.EXACT("Developmental Disabilities") OR MAINSUBJECT.EXACT("Attention Deficit Hyperactivity Disorder") OR MAINSUBJECT.EXACT("Attention Deficit Disorders") OR MAINSUBJECT.EXACT("Neurological Impairments") OR MAINSUBJECT.EXACT("Cerebral Palsy") OR MAINSUBJECT.EXACT("Down Syndrome") OR MAINSUBJECT.EXACT("Fetal Alcohol Syndrome") OR MAINSUBJECT.EXACT("Emotional Disturbances") OR MAINSUBJECT.EXACT("Behavior Disorders") OR MAINSUBJECT.EXACT("Developmental Disabilities") OR MAINSUBJECT.EXACT("Minimal Brain Dysfunction") OR MAINSUBJECT.EXACT("Learning Problems") OR MAINSUBJECT.EXACT("Learning Disabilities") OR MAINSUBJECT.EXACT("Hyperactivity")) AND (MAINSUBJECT.EXACT("Play") OR MAINSUBJECT.EXACT("Play Therapy"))	353
PsycINFO	(Intellectual Development Disorder/ OR "Intellectual Development Disorder (Attitudes Toward)"/ OR Learning Disabilities/ OR Learning Disorders/ OR Developmental Disabilities/ OR Dyspraxia/ OR Hyperkinesis/ OR Movement Disorders/ OR Cerebral Palsy/ OR Traumatic Brain Injury/ OR Hydrocephalus/ OR Fragile X Syndrome/ OR Down's Syndrome/ OR Attention Deficit Disorder with Hyperactivity/ OR Attention Deficit Disorder/ OR Prenatal Exposure/ OR Fetal Alcohol Syndrome/ OR Affective Disorders/ OR Emotional Disturbances/ OR Conduct Disorder/ OR Oppositional Defiant Disorder/ OR Behavior Disorders/ OR Developmental Disabilities/ OR Learning Disabilities/ OR Learning Disorders/) AND (Childhood Play Behavior/ OR Pretend Play/ OR Play Therapy/ OR Role Playing/ OR Playfulness/)	790
PubMed	("Intellectual Disability"[Mesh] OR "Mental Retardation, X-Linked"[Mesh] OR "Learning Disorders"[Mesh] OR "Motor Disorders"[Mesh] OR "Motor Skills Disorders"[Mesh] OR "Stereotypic Movement Disorder"[Mesh] OR "Tic Disorders"[Mesh] OR "Apraxias"[Mesh] OR "Apraxia, Ideomotor"[Mesh] OR "Gait Apraxia"[Mesh] OR "Brain Injuries, Traumatic"[Mesh] OR "Cerebral Palsy"[Mesh] OR "Hydrocephalus"[Mesh] OR "Hydrocephalus, Normal Pressure"[Mesh] OR "Fragile X Syndrome"[Mesh] OR "Down Syndrome"[Mesh] OR "Attention Deficit Disorder with Hyperactivity"[Mesh] OR "Fetal Alcohol Spectrum Disorders"[Mesh] OR "Affective Symptoms"[Mesh] OR "Conduct Disorder"[Mesh] OR "Attention Deficit and Disruptive Behavior Disorders"[Mesh] OR "Social Behavior Disorders"[Mesh] OR "Child Behavior Disorders"[Mesh] OR "Developmental Disabilities"[Mesh] OR "Specific Learning Disorder"[Mesh] OR "Hyperkinesis"[Mesh]) AND ("Play Therapy"[Mesh] OR "Play and Playthings"[Mesh])	1321

Risk of bias (quality) assessments: Assessment of methodological quality of the studies included was done using the Kmet Appraisal checklist, also referred to as 'QualSyst'(Kmet et al., 2004). The Kmet Appraisal checklist was used because it is suitable for assessing quality across a broad range of study designs. The checklist uses ordinal ratings to score reported information (i.e., yes = 2, partial = 1 or no = 0). A score of "not applicable" reduces the possible total Kmet sum of scores, which can be calculated to a percentage score. A score of: >80% is considered strong quality, 60-79% good quality, 50-59% adequate quality, and less than 50% poor quality. Inter-rater reliability for abstract selection and Kmet ratings were established by two independent assessors based on weighted kappa calculations. There was no evident bias in scoring study quality and extractor bias of the reviewers conducting this systematic review.

Data Analysis: A narrative-synthesis was selected to obtain meaningful interpretation of the findings of the included studies and to describe how play is similar or different in children with SHCN; childhood behavioural and/or emotional disorders or physical disabilities from typically developing children.

2.4 Results

Study Selection: A total of 3,933 abstracts were retrieved. Figure 2.1 presents a flow diagram of the abstract reviewing process. The number of records retrieved from each database was: CINAHL = 675, Embase = 794, ERIC = 353, PsycINFO = 790 and PubMed = 1,321. No study was identified through hand search of the reference lists of identified articles. A total of 583 duplicates were removed across the databases, resulting in 3,350 independent studies. Two independent researchers screened the 3,350 records for inclusion by title and abstracts; 207 full text articles were assessed for eligibility. Disagreements between the two reviewers were resolved by consensus and a third reviewer was consulted if agreement could not be reached between the first and second reviewer. In total, 49 studies were identified from full articles. A list of studies published in peer review journals that were excluded and reasons for their exclusion are presented in supplementary Table 2.2 provided. Based on the inclusion criteria, 18 studies were selected for inclusion in this review.

Table 2.2: Articles rejected and the reasons

Article	Study population	Play as outcome measure	No Comparison group at all	Comparison with another group not typically developing children	No full text in English
Pfeifer, L.I., et al., Pretend Play of Children with Cerebral Palsy. Physical & Occupational Therapy in Pediatrics, 2011. 31(4): p. 390-402.			1		
Cress, C.J., K.B. Arens, and A.K. Zajicek, Comparison of Engagement Patterns of Young Children with Developmental Disabilities between Structured and Free Play. Education and Training in Developmental Disabilities, 2007. 42(2): p. 152-164.			1		
Sigafoos, J., D. Roberts-Pennell, and D. Graves, Longitudinal assessment of play and adaptive behaviour in young children with developmental disabilities. Research in Developmental Disabilities, 1999. 20(2): p. 147-162.			1		
De Falco, S., et al., Fathers' play with their Down Syndrome children. Journal of Intellectual Disability Research, 2008. 52(6): p. 490-502.	1				
De Falco, S., et al., Qualità della relazione affettiva madre-bambino e abilità di gioco in bambini con Sindrome di Down. = Quality of affective mother-child relations and game play ability in children with Down's syndrome. Infanzia e Adolescenza, 2008. 7(3): p. 124-137.			1		
De Falco, S., et al., Mothers and Fathers at Play with Their Children with Down Syndrome: Influence on Child Exploratory and Symbolic Activity. Journal of Applied Research in Intellectual Disabilities, 2010. 23(6): p. 597-605.	1				
Fewell, R.R., et al., The relationship between play and communication skills in young children with Down syndrome. Topics in Early Childhood Special Education, 1997. 17(1): p. 103-118.			1		
Ryalls, B.O., et al., A perceptual motor intervention improves play behavior in children with moderate to severe cerebral palsy. Frontiers in Psychology, 2016. 7.			1		
Venuti, P., et al., Play and emotional availability in young children with down syndrome. Infant Mental Health Journal, 2008. 29(2): p. 133-152.			1		
Graham, N., J. Truman, and H. Holgate, An exploratory study: expanding the concept of play for children with severe cerebral palsy. British Journal of Occupational Therapy, 2014. 77(7): p. 358-365.			1		
Johnson-Glenberg, M.C. and R.S. Chapman, Predictors of parent-child languange during novel task play: A comparison between typically developing children and individuals with Down syndrome. Journal of Intellectual Disability Research, 2004. 48(3): p. 225-238.		1			

Ensor, R., et al., Gender differences in children's problem behaviours in competitive play with friends. Br J Dev Psychol, 2011. 29(Pt 2): p. 176-87.		1			
Cordier, R., et al., Comparison of the play of children with attention deficit hyperactivity disorder by subtypes. Aust Occup Ther J, 2010. 57(2): p. 137-45.				1	
Joginder Singh, S., T. Iacono, and K.M. Gray, An Investigation of the Intentional Communication and Symbolic Play Skills of Children with Down Syndrome and Cerebral Palsy in Malaysia. Journal of Early Intervention, 2014. 36(2): p. 71-89.				1	
Sarimski, K., Early play behaviour in children with 5p- (Cri-du-Chat) syndrome. Journal of Intellectual Disability Research, 2003. 47(2): p. 113-120.				1	
Rigby, P. and S. Gaik, Stability of playfulness across environmental settings: a pilot study. Phys Occup Ther Pediatr, 2007. 27(1): p. 27-43.				1	
Cairney, J., et al., Developmental coordination disorder, age, and play: A test of the divergence in activity-deficit with age hypothesis. Adapted Physical Activity Quarterly, 2006. 23(3): p. 261-276.		1			
Cairney, J., et al., Developmental coordination disorder, generalized self-efficacy toward physical activity, and participation in organized and free play activities. Journal of Pediatrics, 2005. 147(4): p. 515-520.		1			
Cazeiro, A.P.M. and J.F.B. Lomônaco, Formação de conceitos por crianças com paralisia cerebral: Um estudo exploratório sobre a influência de atividades lúdicas. = Concept development by children with cerebral palsy: A study about the influence of playful activities. Psicologia: Reflexão e Crítica, 2011. 24(1): p. 40-50					1
Lieber, J., A comparison of social pretend play in young children with and without disabilities. Early Education and Development, 1993. 4(3): p. 148-161.					1
Kennedy, M.D., et al., Play-language relationships in young children with developmental delays: implications for assessment. J Speech Hear Res, 1991. 34(1): p. 112-22.					1
Lalueza, J.L. and A. Perinat, Desarrollo de los significados compartidos en el juego entre adultos y niños con sï1drome de Down. = Development of shared meanings in play between adults and children with Down syndrome. Infancia y Aprendizaje / Journal for the Study of Education and Development, 1994. 67-68: p. 133-146.					1
Ogura, T., A. Notari, and R. Fewell, The relationship between language and play in Down syndrome children. Japanese Journal of Developmental Psychology, 1991. 2(1): p. 17-24.					1
Landau, R., et al., Parenting of 7-month-old infants at familial risk for ADHD during infant's free play, with restrictions on interaction. Infant Behavior and Development, 2009. 32(2): p. 173-182.				1	
Aziz, S., et al. (2017). "Evaluate the Effectiveness of Play Activities on Inattention, Hyperactvity, Impulsivity and Anxiety in ADHD Children of Age Group 6-12 yrs." Indian Journal of Physiotherapy & Occupational Therapy 11(4): 208-211					1

Fleming, A. P., et al. (2017). "Structured Parent-Child Observations Predict Development of Conduct Problems: the Importance of Parental Negative Attention in Child-Directed Play." Prev Sci 18(3): 257-267.			1		
Miller, L. J., et al. (2017). "Play in Natural Environments: A Pilot Study Quantifying the Behavior of Children on Playground Equipment." Journal of Occupational Therapy, Schools & Early Intervention 10(3): 213-231.			1		
Harbourne, R. T., et al. (2018). "Sitting Together And Reaching To Play (START-Play): Protocol for a Multisite Randomized Controlled Efficacy Trial on Intervention for Infants With Neuromotor Disorders." Physical Therapy 98(6): 494-502.					1
Swank, J. M. and S. Smith-Adcock (2018). "On-task behavior of children with attention-deficit/hyperactivity disorder: Examining treatment effectiveness of play therapy interventions." International Journal of Play Therapy 27(4): 187-197.				1	
, ب., et al. (2018). "اخ تلال ذ شاذ گان ب ه بود ب ر گ وی ی ق صه و درماذ ی ب ازی اث ر ب خ شی م قای سه آموزان دانش ف عال ی ب یش/ت وجه ذ قص." Qom University of Medical Sciences Journal 12(8): 59-68.					1
Borg, S. (2009). ADHD and problem-solving in play. Emotional and Behavioural Difficulties, 14(4), 325-336.				1	
Total	2	4	10	7	8

PRISMA Flow Diagram

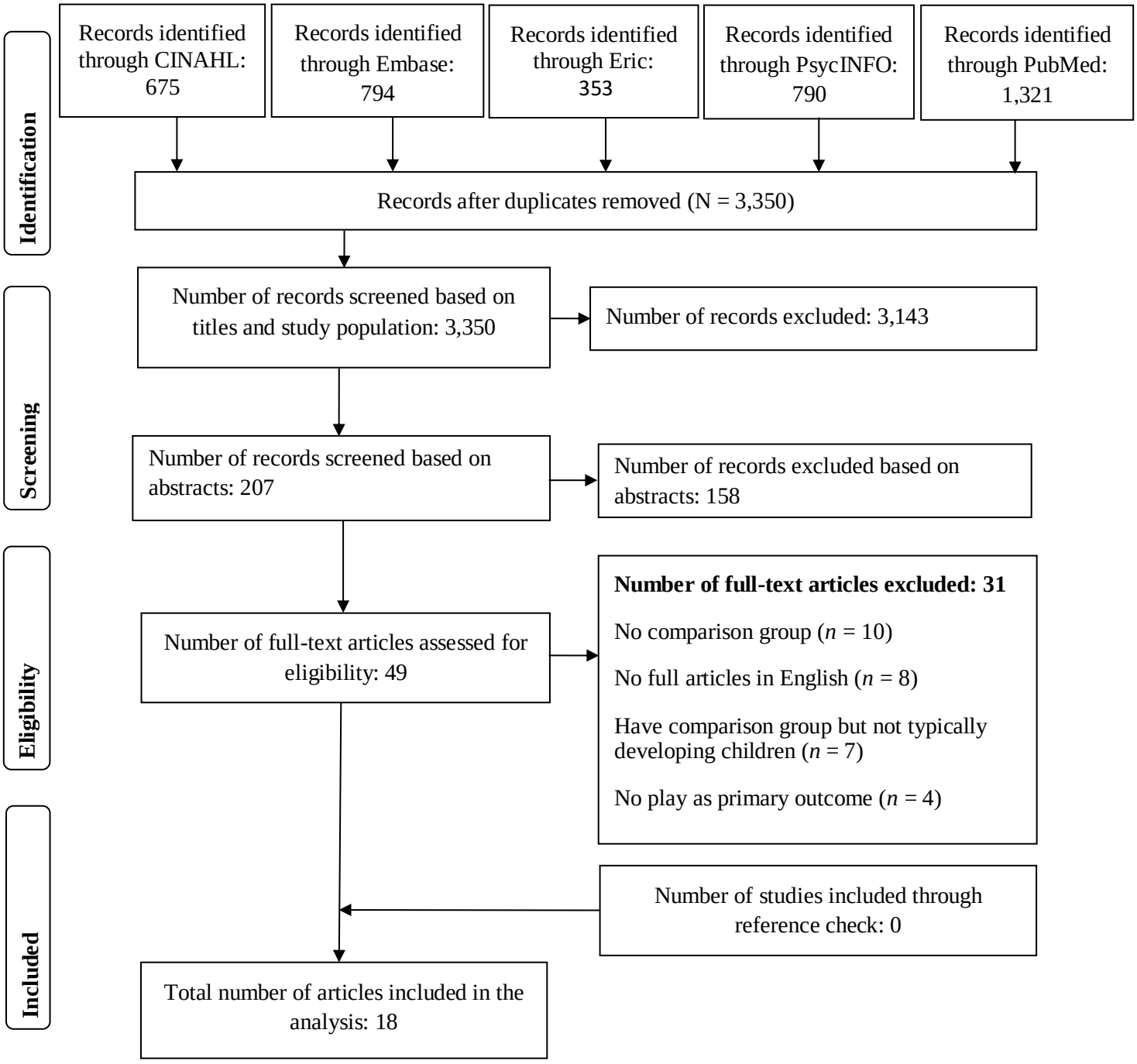


Figure 2.1: PRISMA Flow diagram

Methodological Quality: Eighteen studies published between 1990 and 2018 that compared play in children with SHCN against typically developing children were identified. Of these selected studies, four studies used a Quasi-experimental study design (Barnes et al., 2017; Hsieh, 2012; Landau et al., 2009; Lisy & Porritt, 2016; Okimoto et al., 2000) and thirteen were cross sectional studies (Alessandri, 1992; Angelin et al., 2018; Cairney et al., 2012; Cordier et al., 2010b; File, 1994; Hamm, 2006; Hestenes & Carroll, 2000; Linn et al., 2000; Malone, 2009; Pearton et al., 2014; Skinner et al., 2004; Smyth & Anderson, 2000; Venkatesan & Ravindran, 2012b). A study by Wilkes-Gillan et al. (2016) used a multiple case study design. All the studies included in this systematic review reported adherence to ethical principles to a reasonable extent. Ethical principles reported included obtaining consent from participants, maintaining confidentiality and promoting the safety of children throughout the data collection process. Based on the National Health and Medical Research Council (NHMRC) Hierarchy of Evidence (National Health and Medical Research Council, 2000), five of the studies reviewed were classified as level lll and thirteen were classified as level IV evidence. According to the NHMRC Hierarchy of Evidence, level I studies are systematic reviews of randomised controlled trials (RCTs), level II studies are a well-designed RCTs, and level III studies are, for example, quasi-experimental designs without random allocation. The overall methodological quality ranged from good to strong, with five studies ranked as good and thirteen as strong according to the Kmet ratings.

Risk of Bias: All the studies in this review were at risk of bias due to study design. Twelve of the 18 studies used a cross sectional study design, four used a quasi-experimental design, one used a longitudinal design and another one used a multiple case study design. Of the 18 studies, five had small sample sizes of <30 participants, which limits the generalisability of the findings (Barnes et al., 2017; File, 1994; Hestenes & Carroll, 2000; Linn et al., 2000; Wilkes-Gillan et al., 2016). Allocation concealment was not possible, because all the studies reviewed compared play/playfulness of children diagnosed with a specific condition against typically developing children. Thus, on recruitment it was possible for the participants to know which group they belonged to. Also, as none of the studies had an RCT design, participants were not randomly assigned to different groups. Generally, all studies were at risk of confounding bias.

Participants: The 18 studies included in this review had a total of 1,608 participants aged between 8 months and 13 years, with 67.5% being males. Despite adopting a broad search strategy to capture all chronic illness, only studies with the following diagnosis were found: 184 had ADHD, 125 had general developmental delays, 99 had Developmental Coordination Disorder, 79 had Cerebral Palsy, 31 had cognitive and speech disorders, 15 had prenatal alcohol exposure, and 14 had Down syndrome.

Playmates: All studies reported that participants were observed either playing alone, with another child or with an adult; a summary is provided in Supplementary Table 2.3 and Supplementary Table 2.4. Five studies reported to have observed children from the diagnostic groups playing with a playmate and, in most cases, the playmate was a child who was familiar to the child (Barnes et al., 2017; Cordier et al., 2010c; Skinner et al., 2004; Venkatesan & Ravindran, 2012b; Wilkes-Gillan et al., 2016). Four of five studies that reported on playmates included siblings as the playmates. The proportion of playmates that were siblings were: Cordier et al. (2010c) - 60%, Wilkes-Gillan et al. (2016)- 80%, Barnes et al. (2017) - 62%, and Venkatesan and Ravindran (2012b) had 100%. In some studies, children played in the presence of adults who were either the parent (Landau et al., 2009; Linn et al., 2000; Okimoto et al., 2000) or a caregiver (Hamm, 2006). Five studies observed children playing with their peers in the school setting (either classroom or playgrounds) (Alessandri, 1992; File, 1994; Hestenes & Carroll, 2000; Pearton et al., 2014; Smyth & Anderson, 2000). Four studies reported that participants were observed playing alone (Angelin et al., 2018; Cairney et al., 2012; Hsieh, 2012; Malone, 2009).

Table 2.3: Participants demographics and eligibility criteria

Article	Participants	Playmate/s	Diagnosis/ Condition	Observational Context	Eligibility Criteria
Alessandri (1992)	**Sample size per group:** 20 ADHD +20 without ADHD **Age Range:** 4-5years old **Mean Age:** ***Experimental group***: 52.6 months ***Control group:*** 53.3 months **Gender:** ***Experimental group:*** 17 boys and 3 girls ***Control group:*** 17 boys and 3 girls	**Number of playmates:** NR **Relationship:** Classmates	**Experimental group:** ADHD **Control group:** Typically developing	***Setting*:** Classroom ***Observation time***: 60 min on each child	**Experimental group:** **ADHD:** (a) complaints of short attention span, impulsivity, and hyperactivity at home as reported by mothers; (b) problems persisted for 6 months; (c) behaviour that met DSM-III-R classification for ADHD and no other disorder; (d) a T-score greater than the 84th percentile on the hyperactivity index on the Conners Abbreviated Teacher Questionnaire (CATQ; Goyette, Conners (e) IQ of 80 or higher on the Stanford-Binet Intelligence Scale (4th ed); and (f) No history of treatment with stimulant drugs. **Control group:** (a) no parent complaints of significant behavior problems, (b) no history of ADHD as documented by clinical interview, (c) a score below the 84th percentile on the CATQ (d) an IQ of 80 or higher.
Cordier et al. (2010b)	**Sample size per group** 112 with ADHD + 126 typically growing children **Age Range**: 5-11years ***Mean Age:*** ***Experimental group:*** *106.8 months* ***Control group:*** *103.2 months* **Gender:**	**Number of playmates:** one child with ADHD and one typically developing child in each observation **Relationship:** playmate familiar to child (60% of the	**Experimental group:** ADHD **Control group:** Typically developing	***Setting:*** ***Experimental group:*** playroom in a clinical setting ***Control Group:*** a designated play area at the respective schools ***Observation time:*** 20minutes	**Experimental group:** a) Children had a formal diagnosis of ADHD made by a psychiatrist or paediatrician according to DSM-IV criteria. b) had conditions known to be comorbid to ADHD, such as learning disorders, oppositional defiant disorder, conduct disorder, anxiety disorder, and mood disorder, provided that ADHD was the primary diagnosis c) children with ADHD who were receiving the short-acting forms of methylphenidate given

Article	Participants	Playmate/s	Diagnosis/ Condition	Observational Context	Eligibility Criteria
	Experimental group: 80.3% Boys and 19.7% Girls ***Control group:*** 78.7% Boys and 21.3% Girls	playmates of children with ADHD were siblings because that proportion of the children with ADHD identified that they did not have another usual playmate)			that their duration of action is 3 to 5 hours (American Academy of Child and Adolescent Psychiatry, 2007; Physicians' Desk Reference, 2007). **Control group:** Child who did not have ADHD (i.e., scored below the clinical cut-off for any of the Conners' Parent Rating Scales–Revised [CPRS-R] subscales and DSM-IV scales) and for whom no concerns had been raised about development by a teacher or health professional.
Landau et al. (2009)	**Sample size per group:** 59 34 boys in the risk group and 25 boys in the comparison group **Age Range** ***Experimental group:*** 6.9 -7.36 months Control group: 7.63-8.12 Months **Mean Age:** NR **Gender**: all boys ***Experimental group:*** ***Control group:***	**Number of playmates:** No Playmates **Relationship:** N/A	**Experimental group:** ADHD **Control group:** Children without ADHD	***Setting*:** **Experimental group:** Laboratory room **Control Group**: Laboratory room ***Observation time*:** NR	Experimental group: a score of ≥7, and for recruitment into the comparison group Control Group: a score of ≤3, with background characteristics similar to the risk group. **Exclusion Criteria:** Infants with a history of prenatal, perinatal or postnatal complications, including low birth weight and prematurity, were excluded.
(Okimoto et al., 2000)	**Sample size per group:** 19 children with cerebral palsy and developmental delays + 19 children with no cerebral palsy or developmental delays. **Age Range:**	**Number of playmates:** Only the mother present **Relationship:** Mother	**Experimental group:** Children with cerebral palsy and developmental delays **Control group:**	***Setting***: home setting ***Observation time:*** 15-min free play session	**Experimental group:** Not clearly defined. participants who were videotaped for Hanzlik's (1986) study were used for the current research purpose of scoring the playfulness of young children using the ToP. **Control group:** Not clearly defined.

Article	Participants	Playmate/s	Diagnosis/ Condition	Observational Context	Eligibility Criteria
	Experimental group: 8-32 months ***Control group:***3-18 months ***Mean Age:*** ***Experimental group:***18 months ***Control group:***9 months **Gender:** ***Experimental group:*** 13 Boys and 6 girls ***Control group:***13 Boys and 6 Girls		Children without cerebral palsy and developmental delays		
(Hsieh, 2012)	**Sample size per group** 30 children with CP + 29 age-matched typically developing children **Age Range:** ***Experimental group:*** 72-96 month ***Control group:***72-96 months ***Mean age:*** ***Experimental group:*** 88.08 months ***Control group:*** 88.08 months **Gender:** ***Experimental group:*** 16 boys 13 girls ***Control group:***15 boys and 14 girls	**Number of playmates:** NR **Relationship:** NR	**Experimental group:** Children with cerebral Palsy **Control group:** Typically developing children	***Setting:*** Room designed for free play sessions at each school. ***Observation time:***10-min Individual sessions, designed twice a week to occur over a period of ten weeks.	**Experimental group:** -CP children having moderate to severe fine motor problems as indicated by PDMS-2. -Large motor problems of these subjects included the inability to walk, jump, and abnormal muscle tone. -Muscle tightness influenced the arms in subtle ways. -They also had trouble lifting heavier objects with a certain hand or difficulty grasping objects, holding a pencil, or manipulating objects. -To prevent children with CP have additional intellectual impairments that may affect pretend, all subjects were reported by their teachers as having passed the cognitive components of developmental screen. **Control group:** All control participants were reported by their teachers to be healthy and to display normal learning skills.

Article	Participants	Playmate/s	Diagnosis/ Condition	Observational Context	Eligibility Criteria
(File, 1994)	**Sample size per group.** 14 had mild or moderate cognitive and/or speech and language delays. + 14 typically growing children **Age Range:** **Experimental group:** 56 months **Control group:** 56 months **Mean Age: Experimental group**: 33-73 months; **Control group:** 33-73 months **Gender:** ***Experimental group:*** 24 boys and 4 girls ***Control group:***24 boys and 4 girls	**Number of playmates:** NR **Relationship:** NR	**Experimental group:** Had mild or moderate cognitive and/or speech and language delays **Control group:** Typically growing children	***Setting:*** Classroom ***Observation time:*** two 45-minute visits to each classroom during free play periods.	**Experimental group:** 14 had mild or moderate cognitive and/or speech and language delays. children with physical disabilities and/or severe disabilities were not included in the study, in order to reduce heterogeneity of the sample **Control group:** Each child with disabilities was matched with a typically developing peer from the same classroom who was the same sex and approximately the same age.
(Hestenes & Carroll, 2000)	**Sample size per group:** 8 had disabilities + 21 typically developing **Age Range: Experimental group:** 41-76 months **Control group:** (not stated) **Mean Age:** ***Experimental group:*** 57.8 months ***Control group****:* 53.6 months **Gender:** ***Experimental group:*** 6 boys 2	**Number of playmates: NR** **Relationship:** classmates	**Experimental group:** Children with disabilities **Control group:** Typically developing	***Setting:*** classrooms and outdoor yards at school. ***Observation time:*** observers watched each area of the classroom or play yard containing one or more children for 10 s and then recorded the appropriate information on the	**Experimental group:** not clearly stated **Control group:** not clearly stated

Article	Participants	Playmate/s	Diagnosis/ Condition	Observational Context	Eligibility Criteria
	girls ***Control group:*** 12 boys and 9 girls			map during the next 20 to 30 seconds.	
(Skinner et al., 2004).	**Sample size per group:** 55 Children with mild to moderate developmental delays + 110 play partners with disabilities + 110 play partners without disabilities **Age Range:** ***Experimental group:*** *33-60 months* ***Control group with disabilities:***33-61 months ***Control group without disabilities:*** 35-57 months **Mean Age:** **Experimental group:** 48.99 months **Control with disabilities:** 47.85 months **Control without disabilities:** 46.57 months **Gender:** ***Experimental group:*** 12 girls and 43 boys ***Control with disabilities:*** 24 girls and 86 boys **Control without disabilities:** 24 girls and 86 boys	**Number of playmates**: four different same-sex partners in a standardised dyadic play situation **Relationship:** All familiar to the play mate	**Experimental group:** preschool children with mild to moderate developmental delays. **Control group:** 110 play partners with disabilities and 110 play partners without disabilities	***Setting:*** Outside the classroom in a specially designed play area. ***Observation time:*** two, 15-min sessions with each of the four playmates	**Experimental group**: -All were eligible for special education services under provisions of Part B-Section 619 of the Individuals with Disabilities Act (IDEA; 1999). -Socio-economic status of these children's families varied from 17 to 66 on the Hollingshead Index (Hollingshead, 1975), with a mean of 44. **Control group:** All of the children were enrolled in some type of inclusive program, including a university-based inclusive childcare program, a community-based integrated developmental day program. -Partners were selected from a list of children with a full range of chronological and developmental ages that were normally distributed around their means**.**

Article	Participants	Playmate/s	Diagnosis/ Condition	Observational Context	Eligibility Criteria
(Cairney et al., 2012)	**Sample size per group** (Total of 590), A total of 44 children with DCD and 546 children typically growing children **Age Range:** ***Experimental group:*** not stated ***Control group:*** 108 to 168 months, ***Mean Age:*** ***Experimental group:*** Not stated ***Control Group:*** 137.52 (SD = 1.46). **Gender:** ***Experimental group:*** 25 girls and 19 boys ***Control group:*** NR	**Number of playmates:** NR **Relationship:** N/A	**Experimental group:** DCD **Control group:** Typically growing children	***Setting:*** NR ***Observation time:*** NR	**Experimental group:** All students in grades four through eight from five elementary schools in the Niagara Region of Ontario, Canada. Eighteen children with pre-existing physical limitations, excluded from physical education classes due to medical reasons, were excluded from the study. Eight children with previously known learning disorders were allowed to take part in the study but were excluded from the analyses **Control group:** All students in grades four through eight from five elementary schools in the Niagara Region of Ontario, Canada.
(Smyth & Anderson, 2000)	**Sample size per group** 55 in the DCD + 55 typically developing ***Age range:*** NR ***Mean Age: NR*** **Gender:** ***Experimental group:*** 38 boys and 17 girls ***Control group:*** *38 boys and 17 girls*	**Number of playmates:** Number of playmates varied from playing alone, with 1 other, 2 others, 3 others, 4 others, 5–7 others or with 8+ others**.** **Relationship:** Classmates	**Experimental group:**55 in the DCD **Control group:** 55 typically developing	***Setting:*** classroom, playground ***Observation time:*** Each observation period lasted 5 min and was broken into 30-s intervals.	**Experimental group:** Thirty children in the DCD group scored below the 5th centile on the Movement ABC and 25 scored between the 5th and 15th centile -Children who had been identified as having special educational needs in addition to, or other than, clumsiness were not included -Children diagnosed as having special needs in relation to Asperger's syndrome, general developmental delay and attention deficit disorder were excluded. **Control group:**

Article	Participants	Playmate/s	Diagnosis/ Condition	Observational Context	Eligibility Criteria
					Matched on gender, age and verbal ability
(Venkatesan & Ravindran, 2012a)	**Sample size per group** 42 children with developmental disabilities + 42 siblings **Age Range: NR** ***Mean Age*** ***Experimental group:*** (129.6 months) and girls (97.2 months) ***Control group***: boys (138 months) and girls (139.2 months) **Gender:** ***Experimental group:***23 boys and 19 girls ***Control group:*** 17 boys and 25 girls	**Number of playmates:** Varied (depended on the number of siblings in family, available for the study). **Relationship:** siblings	**Experimental group:** Children with Developmental disabilities which include mental retardation (14), hearing loss (8) and others (20). The others included speech delays, autism, fluency disorders, multiple disabilities, children with emotional and conduct disorders. **Control group:** Typically developing siblings	***Setting:*** NR ***Observation time:*** NR	**Experimental group:** Children with developmental disabilities attending Therapy clinics at all India Institute of Speech and Hearing, under the ministry of Health and family Welfare, Government of India, Mysore. -Each individual underwent an assessment through case history and diagnostics assessment which combined opinions from specialist like ENT, neurology, Clinical Psychology, physiotherapy, occupational therapy, audiology and speech language pathology. **Control group:** Offspring sharing the same biological origins and resident members of their natural home settings and those who have continually lived together under same roof as one family along with their parents or extended family members as the case could be.
(Linn et al., 2000)	**Sample size per group** 14 with Down syndrome + 14 typically developing children **Mean Age:** ***Experimental group:*** 29.10 Months ***Control group:*** 28.70 Months **Age Range: NR** **Gender:** ***Experimental group***: 7 girls	**Number of playmates:** Child playing alone, but mother and the research assistant are present in room **Relationship:** N/A	**Experimental group:** 14 with Down syndrome **Control group:** 14 typically developing children	***Setting:*** standardised playroom ***Observation time:*** The play session lasted from 30 to 60 minutes depending upon the child's involvement with the toys	**Experimental group:** -a developmental age between 20 and 40 months, as assessed with the Mental Scales of the Bayley Scales of Infant Development (Bayley, 1993), and --the ability to sustain involvement in the play session for at least 30 minutes (remain in the play room and not indicate verbally or non-verbally the desire to terminate the session). All children were from Caucasian, English-speaking families and lived with at least one biological parent. **Control group:** Matching individual subjects with subjects from the

Article	Participants	Playmate/s	Diagnosis/ Condition	Observational Context	Eligibility Criteria
	and 7 boys ***Control group:*** 7 girls and 7 boys				group of children with Down syndrome on developmental age (+/-2 months), sex, ethnicity, and mother's level of education.
(Pearton et al., 2014)	**Sample size per group** 15 children who had positive histories of Prenatal Alcohol Exposure (PAE) + 15 Typically developing children. **Age Range: NR** **Mean Age (years):** ***Experimental group:***84.6 (0.50) ***Control group:*** 81.72 (0.58) **Gender:** ***Experimental group:***8 boys and 7 girls ***Control group:***7 boys and 8 girls	**Number of playmates:** NR **Relationship**: N/A	**Experimental group:** 15 children who had positive histories of Prenatal Alcohol Exposure (PAE) **Control group:** 15 Typically developing children.	***Setting:*** School playground ***Observation time:*** 15 minutes	**Experimental group:** Participants needed to have a history of minimal to heavy PAE, Children were excluded from the study if they had histories of exposure to other drugs in utero, except nicotine. -Children were also excluded from the study if they currently or previously received treatment or play or socio-behavioural problems. -Children were excluded if they had known major neurodevelopmental or psychiatric disorders, such as Autism or cerebral Palsy **Control group:** This group included 15 children who did not have a history of PAE. No history of PAE was confirmed by parents or guardians during a semi-structured interview discussing the children's developmental history.
(Malone, 2009)	**Sample size per group** 17 children with intellectual disabilities + 17 typically growing children **Age Range:** NR **Mean Age:** ***Experimental group:*** 52.35 months (SD = 14.01 ***Control group:*** CA of 27.76 months (SD = 11.37) **Gender:**	**Number of playmates:** child played independently **Relationship:** N/A	**Experimental group:** 17 children with intellectual disabilities **Control group:** 17 typically growing children	***Setting:*** home-based independent play situation and a classroom-based free play situation. ***Observation time:*** 30-minute video	**Experimental group:** All children were recruited from Patterns of Home- and Classroom-based Toy Play 335 seven inclusive preschool programmes (i.e., general education programmes into which children with developmental concerns were enrolled). **Control group:** Groups were matched, child-by-child, on cognitive developmental age (DA) and gender.

Article	Participants	Playmate/s	Diagnosis/ Condition	Observational Context	Eligibility Criteria
	Experimental group: 10 boys and 7 girls ***Control group:*** 10 boys and 7 girls				
(Hamm, 2006)	**Sample size per group** 20 children with disabilities + 20 children without disabilities **Age Range: NR** **Mean Age:** ***Experimental group:*** 16.3 months ***Control group:*** 16.2 months. **Gender:** ***Experimental group:***14 boys and 6 girls ***Control group:*** 13 boys and 7 girls	**Number of playmates:** Caregivers were instructed to engage in typical play with their child**,** (one caregiver) **Relationship:** Caregiver	**Experimental group:** 20 children with disabilities. Types of disabilities varied, and ranged from mild to severe limitations **Control group:** 20 children without disabilities	***Setting:*** child's natural play environment**.** a room in the family home where the child typically engaged in play ***Observation time:*** a 20-minute	**Experimental group:** All families had a socioeconomic status of working or middle class and all children, with the exception of one boy with a developmental disability, resided with both parents. -All participating parents had completed high school and most were college educated (15 parents of children without disabilities and 14 parents of children with disabilities). -All fathers in both groups were employed outside the home. Nine mothers of children with disabilities worked outside -The home, whereas 16 mothers of children without disabilities worked outside the home. **Control group:**
(Angelin et al., 2018)	**Sample size per group** 30 children with CP and 30 children with TD, **Age Range:** aged 36–72 months (with a tolerance of four months after the sixth birthday **Mean Age:** ***Experimental group:*** *Mean* 54.6months SD 12.4 ***Control group:*** *Mean* 53.9months, SD10.9	**Number of playmates:** NR **Relationship:**	**Experimental group:** 30 children with CP **Control group:** 30 children with Typically Developing,	***Setting:*** Private room, provided by the rehabilitation centre (for children with CP) or at school (for children with TD), without the interference of external stimuli. ***Observation time:*** NR	**Experimental group:** children with CP were; (1) diagnosed with CP, (2) age 3–6 years, (3) able to understand simple commands, and (4) consented by parents to participate in this study. **Control group:** The group of children with TD was compared to the group of children with CP in terms of age and sex.

Article	Participants	Playmate/s	Diagnosis/ Condition	Observational Context	Eligibility Criteria
	Gender: ***Experimental group:*** *19 boys and 11 girls* ***Control group:*** 15 boys and 15 girls				
(Wilkes-Gillan et al., 2016)	**Sample size per group** 5 children with ADHD and 5 playmates **Age Range:NR** **Mean Age:** 19 months; SD; 0.8 for all participants ***Experimental group:*** ***Control group:*** **Gender:** ***Experimental group:*** *4 boys and 1 girl* ***Control group:*** *2 boys and 3 girls*	**Number of playmates:** 5 **Relationship:** 4 were siblings and 1 was a friend	**Experimental group:** 5 children with ADHD **Control group:** 5 playmates	***Setting:*** clinic playroom ***Observation time:*** 20 mins	**Experimental group:** Three children with ADHD presented with the inattentive subtype with T-scores above the clinical cut-off (>70) on the inattention subscale (mean group inattention scale T-score=74.3; SD;7.9). Two children with ADHD presented with the hyperactive subtype with T-scores above the clinical cut off (>70) on the hyperactive scale subtype (mean group hyperactive scale T-score¼64; SD¼11.2) **Control group:** Playmates had T-scores below the borderline clinic cut-off (<65) on all symptom scales.
(Barnes et al., 2017).	**Sample size per group** 13 children with ADHD and 13 TD children **Age Range: NR** **Mean Age:** ***Experimental group:*** *120 months SD (2.1)* ***Control group:*** *111.6 months SD (2.3)* **Gender:** ***Experimental group:*** *11 boys*	**Number of playmates:** 13 **Relationship:** 8 of the 13 playmates were siblings	**Experimental group: 13 children with ADHD** **Control group: 13 TD children**	***Setting:*** home environment and in the clinic ***Observation time:*** 20 minutes	**Experimental group:** Children with ADHD who participated in the 10-week RCT intervention 12 months earlier (Wilkes-Gillan et al., 2016) were invited to participate in the study with a playmate. -Participating children's level of ADHD symptoms were measured using the Conners Comprehensive Behavior Rating Scales (CCBRS), with a T score ≥65 on one ADHD DSM-IV subscale indicating clinical level of symptoms**.** **Control Group:** Playmates were required to be of similar age and either a peer, sibling or cousin who regularly spent time with the child with ADHD.

Article	Participants	Playmate/s	Diagnosis/ Condition	Observational Context	Eligibility Criteria
	and 2 girls ***Control group:*** *6 boys and 7 girls*				

Notes. Abbreviations: M = Mean; SD = Standard deviation; TD = typically developing; NR = not reported; N/A = not applicable;

Setting refers to place/location were data collection was done; Observation time refers to time taken by researchers observing the children whilst engaged in play

Table 2.4: Study aim, design, quality, outcome measures and outcomes

Study	Study aim	Study Design	Quality of the studies (KMET)	Primary measures used to measure play and secondary outcome measure/tools used	Findings on play/playfulness	Other findings
Alessandri (1992)	To observe the play and non-play behaviours of ADHD and non-ADHD preschool-age children in a free play situation.	Cross sectional Study	76.9%	**Primary outcome measure:** Quality of social participation and level of cognitive play Rubin (1989). Used adapted tool, (actual name not mentioned **Secondary Outcome Measure:** non-play categories were coded, tool not mentioned clearly	ADHD children engaged in less dramatic play compared with non-ADHD children (M = 413.35 vs. 643.25, $p < .05$). Although there were no differences in the frequency of solitary play between the two groups, ADHD children engaged in less parallel (M =912.25 vs. 1330.25) and less group play (M = 162.05 vs. 294.75, all $p < .01$) compared with non-ADHD children.	ADHD children engaged in greater negative affective exchanges when with adults compared with non-ADHD children (M = 62.75 vs. 12.50, $F (1, 38) = 12.64$, $p < .01$). Moreover, ADHD children engaged in fewer peer conversations than non-ADHD children, $F (1, 38) = 8.64$, $p < .01$.
Cordier et al. (2010b)	To examine the similarities and differences in play behaviour of children as having ADHD and typically developing children.	Cross sectional study		**Primary outcome measure:** ToP (Bundy, 2004) **Secondary Outcome Measure** Conners' Parent Rating Scales–Revised [CPRS-R] subscales (Hale, How, Dewitt, & Coury, 2001)	Children with ADHD were less playful than the typically developing children (ADHD mean measure score = 1.09; ADHD standard deviation = 1.28; Control mean measure score = 1.99; control standard deviation = 0.82; $t = -13.9$; $p < .01$; $df = 125$).	Children with ADHD performed significantly more poorly on five of the eight social items: shares (4); support (5); intensity (11) and skill of social play (12); and skill in responding to cues (29) (Table 3). However, of the remaining three social items, children with ADHD performed significantly better than typically developing children on skill to negotiate (2). There was not a significant difference for the skill to initiate (1) or extent of social play (10).

Study	Study aim	Study Design	Quality of the studies (KMET)	Primary measures used to measure play and secondary outcome measure/tools used	Findings on play/playfulness	Other findings
Landau et al. (2009)	-To determine if there were differences in patterns of interaction of mothers and fathers with their 7-month-old boys at familial risk for ADHD	Longitudinal Study	73%	**Primary outcome measure:** Coding **Secondary Outcome Measure** Laboratory Temperament Assessment Battery (LAB-TAB) (Goldsmith & Rothbart, 1996), DSM-IV (American Psychological Association, 1994) Tridimensional Personality Questionnaire (Cloninger, 1987) Conners Adult ADHD Rating Scale (CAARS; Conners, Erhardt, & Sparrow, 1998)	No differences for Needs Help were found between groups (The experimental and the control group), F (1,56) = .89, p= .35, η_p^2= .016, or between the infant's behaviour in the presence of the mother and in the presence of the father, F(1,56) = 1.04, p = .31, η_p^2 = .018. Nor was the interaction between group and parent significant, F(1,56) = .02, p = .90, η_p^2 = .000. The percentage of infants who tried to involve their father was significantly higher than the percentage who tried to involve their mother, = 46.99, df=1, p < .001.	No differences were found for group or for parent in the ANOVA analysis. Nor was the interaction between parent and group significant. However, when analyzed separately, the between-group difference for mother's behavior was significant, t(45) =−2.34, p = .02, g = .569.
Okimoto et al. (2000)	-To determine whether the ToP (Version 3) was a reliable and valid instrument to assess young children. -To compare the playfulness of young children with cerebral palsy and developmental delays with that of peers who are typically	Quasi-experimental design	84.6%	**Primary outcome measure:** The ToP, Version 3 (Bundy, 1997b) **Secondary Outcome Measure** N/A	The mean score of the children who were typically developing was significantly higher on the ToP than the mean score of their matched counterparts with cerebral palsy and developmental delays (t = –3.938, p = .0005).	There was no significant difference between the mean gain score of the children whose mothers received the intervention and that of the children who received NDT (t = .562, p = .583).

Study	Study aim	Study Design	Quality of the studies (KMET)	Primary measures used to measure play and secondary outcome measure/tools used	Findings on play/playfulness	Other findings
	developing -To compare the effect of an intervention aimed at improving mother–infant interactions with that of neurodevelopmental treatment (NDT) on the children's playfulness.					
Hsieh (2012)	-To examine affective expressions and imagination in children with CP as a function of ordinary versus adaptive pretend play.	Quasi-experimental design	84.6%	**Primary outcome measure:** Play Scale-Brief Rating (APS-BR) (Sacha Cordiano, Russ, & Short, 2008). **Secondary Outcome Measure:** Fine Motor Scale of the Peabody Developmental Motor Scales, 2nd edition (Folio & Fewell, 2000)	Multivariate analysis of variance (MANOVA) was use to investigate the relationship between Child Group (CP and typically developing children) and Play Type (adaptive and ordinary pretend play). Children with CP showed significantly more affective expression for adaptive pretend play than for ordinary pretend play, $F(1, 28) = 96.475$, $p = 0.000$, $\eta_p^2 = 0.775$. The results show more significant positive changes of imagination behaviors occurring in children with CP during adaptive pretend play, $F(1, 28) = 107.205$, $p = 0.000$, $\eta_p^2 = 0.793$.	The mean scores for the APS-BR in the CP group increased across adaptive pretend play sessions as hypothesized ($F = 192.783$, $p = 0.000$, $\eta_p^2 = 0.043$). Analyses illustrated that play type differences appeared to influence the emotion expression and imagination of CP children during the pretend play session.
File (1994)	-To examine the cognitive and social complexity of their play and their	Cross sectional study	76.9%	**Primary outcome measure:** Coding tool based upon the Rubin, Maioni, and Hornung	The proportion of time children engaged in play activities was identical for	-The main effect for children's developmental status was significant, F(1,

Study	Study aim	Study Design	Quality of the studies (KMET)	Primary measures used to measure play and secondary outcome measure/tools used	Findings on play/playfulness	Other findings
	interactions with teachers.			(1976) adaptation of the work of Parten and Smilansky. **Secondary Outcome Measure:** -The Peer Relation Rating Scale was adapted from Ladd and Muth (1990). -Assessment of Teacher Role Scale developed for this study consisted of 6 vignettes.	children with disabilities and developing typically (70%). The 28 participants spent an average of 56% of their play at the functional level (range =.18-.98).	25), p= 9.41, ηp^2= .005. -Children were uninvolved with teachers for two thirds (67%) of the time. -T-tests revealed no differences in how often teachers were uninvolved, involved in routines, or watched children according to the children's developmental status.
Hestenes and Carroll (2000)	-To describe the context of play as well as to better understand the experience of inclusive classrooms for children with and without disabilities, young children's play interactions and beliefs in inclusive preschool settings were also examined	Cross sectional study	88.5%	**Primary outcome measure:** scan-sampling technique (Nabors, 1995) **Secondary** Outcome Measure: Competency Ratings for Disabilities (Diamond, 1994; Diamond & Hestenes, 1996; Diamond et al., 1997)	Typically developing children spent over half their time in cooperative play. Children with disabilities spent about one third of their time in cooperative play and one third of their time in solitary play.	-Typically developing children were significantly less likely to interact with their peers with disabilities (14.3%) than would be expected (29%). -A paired-sample t test showed that children with disabilities also spent significantly less time interacting with their typically developing peers (33%) than was expected (71%; t(8) 5.83, p.01). -There were no differences in typically developing children's reported preferences to play with peers without disabilities (M 2.07, SD 0.37) versus peers with

Study	Study aim	Study Design	Quality of the studies (KMET)	Primary measures used to measure play and secondary outcome measure/tools used	Findings on play/playfulness	Other findings
						disabilities (M 2.04, SD 0.49)
Skinner et al. (2004)	-To examine how total duration of social play of preschool children with disabilities varied as a function of Both chronological and Developmental age of their social partners.	Cross sectional study	66.7%	**Primary outcome measure:** Parten's social play categories. Parten's (1932) **Secondary Outcome Measure:** Behavioral observations conducted were using Observer 3.0 for Windows, with the Video Tape Analysis (Noldus Information system Technology, 1996). Battelle Developmental Inventory. The Battelle Developmental Inventory (BDI; Newborg, Stock, Wnek, Guidubaldi,& Svinicki,1988)	Children with lower developmental ages displayed less associative play with more advanced partners. A child at a more advanced developmental level (developmental age of 45 months), however, would exhibit longer total duration of associative play with partners of more advanced development than of Partners with less advanced developmental (B = 6.23, age effect size = .23).	Focal child with developmental age of 34 months would not exhibit different age durations of associative play with partners different of developmental levels(B =- .69, effect size= .025).
Cairney et al. (2012)	To investigate the effect of gender on the relationship between Developmental Coordination Disorder (DCD) and self-reported participation in organized and recreational free-play activities	Cross sectional study	86.3%	**Primary outcome measure:** The Participation Questionnaire (PQ) (Hay, 1992) **Secondary Outcome Measure** Participation Questionnaire Children with DCD reported lower self-efficacy toward physical activity (M = 62.16, SD = 10.52) than did children without DCD (M = 48.30, SD = 11.90). The Children's Self-perception	Children with DCD (M = 13.79, SD = 4.22) were less likely than their motor proficient peers (M = 14.81, SD = 4.72) to engage in recreational free play activities.	Children with DCD reported lower self-efficacy toward physical activity (M = 62.16, SD = 10.52) than did children without DCD (M = 48.30, SD = 11.90).

Study	Study aim	Study Design	Quality of the studies (KMET)	Primary measures used to measure play and secondary outcome measure/tools used	Findings on play/playfulness	Other findings
				of Adequacy in and Predilection for Physical Activity (CSAPPA) scale (Hay, 1992). Short form Bruininks-Oseretsky Test of Motor Proficiency (BOTMP-SF; Bruininks, 1978).		
Smyth and Anderson (2000)	-To determine whether a child's performance on a test of motor ability is related to later involvement in both social and physical activities in the school playground. -To explore the relationship between the physical demands of play and the sizes of the groups in which it takes place and how this changes with age.	Cross sectional study	87.5%	**Primary outcome measure:** Psion Workabout computer using a detailed coding scheme developed in the Observer software system. Boulton and Smith (1993) **Secondary Outcome Measure** Movement Assessment Battery for Children (the Movement ABC; Henderson & Sugden, 1992).	Most children spent their playtime in single sex groups ($F(2,106) = 524.4$, $p < 001$). Boys were observed in the less active group more often than in the more active group ($F(1,74) = 30.47$, $p < .001$), but that there was no significant interaction between these factors ($F(1,74) = 1.96$, $p > .05$).	There was a significant effect of group membership ($F(1,102) = 7.34$, $p < .01$), with children in the DCD group spending more time alone, no effect of age, and no interaction ($F < 1$ in both cases). In a separate analysis there was no reliable effect of gender $F(1,106) = 1.59$, $P > .05$) and no interaction between gender and group membership ($F < 1$).
Venkatesan and Ravindran (2012a)	-To delve deep and specifically into play behaviours and activities between affected and unaffected siblings in relation to variables like age, gender, education, type of disability and	Cross sectional exploratory research	75%	**Primary outcome measure:** Play Activity Checklist for children with Mental Retardation (PACK-MR) (Khoshali and Venkatesan, 2010) **Secondary Outcome Measure**	Children with developmental disabilities (42) manifest varieties of play behaviours like maintains eye to eye contact with peers (n: 37/42; 88.1%), shares own belongings/play materials with peers (n: 35/42; 83.3%).	Children attending special schools (N:23; Mean: 14.9; SD:4.7) as well as regular schools (N:16; Mean: 9.2; SD: 2.6) appear to have advantage and range of play behaviours compared to children with no school

Study	Study aim	Study Design	Quality of the studies (KMET)	Primary measures used to measure play and secondary outcome measure/tools used	Findings on play/playfulness	Other findings
	number of siblings			N/A		exposure (N:3; Mean: 1.1; SD: 0.7) F: 22.79; p<0.001).
Linn et al. (2000)	-To investigate how children with Down syndrome performed without the typical constraints of time and adult directives	Cross sectional study	91.6%	**Primary outcome measure:** Identification of play episodes followed procedures established by McCune Nicolich (1983). **Secondary Outcome Measure:** coded based on categories determined by Krakow and Kopp (1983).	All subjects played for at least 30 minutes Children with Down syndrome fell into two groups; short players (n=4) and long players (n=10). After 47 minutes, the 10 long players with Down syndrome discontinued play at a nearly uniform rate, until play for all children was stopped at 60 minutes. Typically developing children first ended play at 33.4 minutes and the rate of discontinuation remained steady until play for all children was stopped at 60 minutes	Children with Down syndrome interrupted play more often to engage in social behavior than their typically developing mental-age-matched peers. Children with Down syndrome had an average of 1.36 social episodes (range 0–8), and typically developing children had an average of .71 social episodes (range0–4).
Pearton et al. (2014)	-To investigate the differences in playfulness of children with and without prenatal alcohol exposure.	Cross sectional comparative study	95.4%	**Primary outcome measure:** Test of playfulness (ToP) **Secondary Outcome Measure:** Questionnaire was used to determine which children met the inclusion and exclusion criteria as well as for inter-group comparisons on demographic information	The PAE group were found to have significantly lower overall mean playfulness scores than the reference Group (t=2.51; df=28; p=0.02).	The PAE group was found to have scored significantly lower on 5 of the 12 ToP items related to social play than their reference group counter parts. Children with PAE were found to score significantly lower than the reference group on two other items

Study	Study aim	Study Design	Quality of the studies (KMET)	Primary measures used to measure play and secondary outcome measure/tools used	Findings on play/playfulness	Other findings
						not exclusively related to social play, namely 'Transitions' from one play activity to another (t=7.74; df=1; P =0.01), and 'Modifies' activity to maintain challenge or make the activity more fun (t=5.60; df=1; P=0.03)
Malone (2009)	-To analyse, the within and between group patterns of play demonstrated by preschool children with and without intellectual disabilities in home-based independent play and classroom-based free-play situations are presented	Cross sectional study	75%	**Primary outcome measure:** Coded for categorical and sequential play **Secondary Outcome Measure:** Battelle Developmental Inventory (BDI; Newberg, Stock, Wneck, Guidubaldi, & Svinicki, 1984)	During the classroom-based free play situation children with intellectual disabilities spent more time engaged in constructive play than either functional play or pretend play. A statistically significant effect emerged for these children's classroom based categorical play variables [$F(1.25, 20) = 9.07$, $p < .01$; $\eta_p^2 = .36$]. During the home-based play situation children without intellectual disabilities spent more time engaged in constructive play than either functional play or pretend play. As demonstrated by children without intellectual disabilities was statistically	During the home-based play situation children with intellectual disabilities spent more time engaged in unordered multi-scheme play sequences than either single scheme play sequences or ordered multi-scheme play sequences. During the classroom-based free play situation children with intellectual disabilities spent more time engaged in single scheme play sequences than either unordered multi-scheme play sequences or ordered multi-scheme play sequences. The overall analysis of length of play sequences was neither statistically significant

Study	Study aim	Study Design	Quality of the studies (KMET)	Primary measures used to measure play and secondary outcome measure/tools used	Findings on play/playfulness	Other findings
					significant [F(2, 32) = 3.84, p < .000; ηp^2=.60]	nor meaningful [F(2, 32) =2.1.47, p .25; = .08]. During the classroom-based free play situation children without intellectual disabilities spent more time engaged in single scheme play sequences than either unordered multi-scheme play sequences or ordered multi-scheme play sequences.
Hamm (2006)	-To examine the reliability and validity of the Test of Playfulness (ToP) and the Test of Environmental Supportiveness (TOES), to compare playfulness and environmental support of play in children with and without developmental disabilities, and to examine the correlation between the ToP and the TOES.	Cross sectional study	92.3%	**Primary outcome measure:** Test of Playfulness (ToP). The ToP (version 4.0) (Bundy, 1991) **Secondary Outcome Measure** Test of Environmental Supportiveness (TOES). Bundy (1999)	Children with developmental disabilities were less playful than their peers without developmental disabilities, regardless of the presence of siblings or gender The ToP is both reliable and valid and may provide clinicians and researchers with a practical means of measuring the construct of playfulness	Reliability and validity of the TOES as a measurement of the environmental support of play was also supported Data from 100% of the participants and raters conformed to the Rasch model All items (100%) fit the model supporting that the ToP reflects a unidimensional construct of playfulness
Angelin et al. (2018)	-To compare the play performance of preschool children in TD and children with CP, and	Cross sectional study	96.2%	**Primary outcome measure:** The revised Knox Preschool Play Scale (KPPSr) (Knox, 2002). **Secondary Outcome**	The mean (15.20, SD 21.142) obtained by the study group was always lower than the mean (40.97 SD 8.977) obtained by the control group,	These results indicate that a greater impairment of manual function and functional mobility led to poor engagement with

Study	Study aim	Study Design	Quality of the studies (KMET)	Primary measures used to measure play and secondary outcome measure/tools used	Findings on play/playfulness	Other findings
	investigate the relationship between the level of functional mobility and manual function on play in these children.			**Measure** Gross Motor Function Classification System – Expanded and Revised (GMFCS – E&R) (Palisano, Rosenbaum, Bartlett, & Livingston, 2008) Manual Ability Classification System (MACS), respectively (Eliasson et al., 2006).	presenting difference statistically evident between the groups in all dimensions, using a t-test for independent samples. No significant associations between the manual function and functional mobility and the pretense/symbolic play and participation dimensions of the KPPSr. This suggests that these dimensions are not directly influenced by motor skills in children with CP.	recreational activities requiring those functions.
Wilkes-Gillan et al. (2016)	-To investigate if children and parents who had engaged in the parent-delivered intervention 18 months previously would benefit from an additional dose of technology-based intervention targeting children's social play skills.	Multiple case study	96.2%	**Primary outcome measure:** Test of Playfulness (Bundy, 2004) **Secondary Outcome Measure** Parent-rated Conners Comprehensive Behavior Rating Scales (CCBRS) (Conners, 2008).	Two children (pairs 2, and 5) showed an increase in their social play skills. The children with ADHD in these pairs had an eight- and 13-point difference in their pre- and post-intervention scores. Three children (pairs 1, 3 and 4) had a decrease in scores. For the ToP scores of the playmates, three children (pairs 1, 2 and 3) showed consistent social play skills, one an increase in skill (pair 5) and one a decrease (pair 4).	described two main groupings of content through their interviews: (1) that as parents they felt better able to read and support their child and felt empowered as a result, (2) that next steps for the intervention were necessary.

Study	Study aim	Study Design	Quality of the studies (KMET)	Primary measures used to measure play and secondary outcome measure/tools used	Findings on play/playfulness	Other findings
Barnes et al. (2017)	-To determine whether children with ADHD and their playmates maintained improvements in their social play skills, 12 months after their involvement in the RCT. The secondary aim was to evaluate the social skills and parent–child relationships of children with ADHD and their playmates.	Experimental study	95.5%	**Primary outcome measure:** Test of Playfulness (ToP) (Bundy, 2004) **Secondary Outcome Measure** Social Skills Improvement System (SSIS Gresham & Elliott, 2008) Parenting Relationship Questionnaire (PRQ) (Kamphaus & Reynolds, 2006) Conners Comprehensive Behavior Rating Scales (CCBRS)(Conners, 2008)	No significant change was shown between mean ToP scores of the children with ADHD in the home environment (time points A and C; t=0.96, P=0.36, d=0.68). A significant decrease was shown between mean ToP scores of the children with ADHD in the clinic environment (time points B and D = -2.38, P=0.04, d= -0.57). No significant difference was shown between mean ToP scores of the playmate group in the home (time points A and C; t = 0.25, P = 0.81, d = 0.48) or clinic (time points B and D; t = -1.63, P = 0.14, d = -0.74).	both groups scored within a developmentally appropriate range on all SSIS scales, with the ADHD group scoring significantly lower than the playmate group. Children with ADHD scored within the average range for five of the seven PRQ scales. Playmates scored within the average range for six of the seven PRQ scales.

Notes. M - Mean: SD - Standard deviation; F = F ratio of ANOVA, *p* = probability value; η_p^2 - partial eta square: effect size for ANOVA; g = Hedges'

Study Settings: Participants were observed playing either at home, school or at a clinic. Seven of the 18 studies reported that participants were observed at school. Of these seven studies, three studies were conducted in the classroom (Alessandri, 1992; File, 1994; Hsieh, 2012), two studies in the play grounds (Pearton et al., 2014; Skinner et al., 2004) and two studies were conducted both in the classroom and in the playground (Hestenes & Carroll, 2000; Smyth & Anderson, 2000). Two studies observed typically developing children in a school environment and the diagnostic group in the clinic (Angelin et al., 2018; Cordier et al., 2010b). Two studies were carried out in the home setting (Hamm, 2006; Okimoto et al., 2000), while two studies (Barnes et al., 2017; Malone, 2009) observed the children in both the home and the clinic environment. A study by Barnes et al. (2017) used a playroom at the clinic to carry out their observations. Two of the 18 studies observed the children playing in a custom designed playroom (Landau et al., 2009; Linn et al., 2000). Only two studies did not report the settings where the child was observed playing (Cairney et al., 2012; Venkatesan & Ravindran, 2012b).

Observation time: The observation time varied from 10 seconds to 60 minutes per session. Seven of the 18 studies observed each participant for between 15 and 20 minutes (Barnes et al., 2017; Cordier et al., 2010b; Hamm, 2006; Okimoto et al., 2000; Pearton et al., 2014; Skinner et al., 2004). Observation time was not reported in four studies (Angelin et al., 2018; Cairney et al., 2012; Landau et al., 2009; Venkatesan & Ravindran, 2012b).

Play Assessment tools: Although all the studies reviewed involved observing children playing, different assessment tools were used. The Test of Playfulness (Skard & Bundy, 2008) was used in six of the 18 studies reviewed (Barnes et al., 2017; Cordier et al., 2010b; Hamm, 2006; Okimoto et al., 2000; Pearton et al., 2014). Other assessment tools used include the revised Knox Preschool Play Scale (KPPSr; Knox, 1997) which was used by Angelin et al. (2018), the Play Scale-Brief Rating (APS-BR) (Sacha Cordiano & Short, 2008) used by Hsieh (2012) and the Play Activity Checklist for children with Mental Retardation (PACK-MR; Khoshali & Venkatesan, 2010) used by Venkatesan and Ravindran (2012b).

One study by Cairney et al. (2012) used a participation questionnaire to collect data on active play. Eight studies used various coding approaches to record and analyse play among children (Alessandri, 1992; File, 1994; Hestenes & Carroll, 2000; Landau et al., 2009; Linn et al., 2000; Malone, 2009; Skinner et al., 2004; Smyth & Anderson, 2000). For example the study by Skinner et al. (2004) used Parten's social play categories (Parten, 1933) and

Hestenes and Carroll (2000) used a scan-sampling technique developed by Nabors (1995). A study by Smyth and Anderson (2000) used the Psion Workabout computer using a detailed coding scheme developed in the Observer software system for coding (Boulton & Smith, 1993). The coding systems and behaviours were operationally defined differently across all the studies that involved behavioural coding, indicating a lack of evidence of validity. However, interrater reliability of observers was established for some of studies ranging between 80-100% agreement. Most studies in this review were at risk of observation bias due to a lack of blinding of the researchers for outcomes.

Play of children with SHCN: The studies reviewed examined different aspects of play, which makes it difficult to synthesise the findings. However for the purposes of comparing play patterns, findings were extracted and grouped into four themes: overall play, play duration, types of play, and play behaviours (see Table 2.5). Of the 18 studies included in this systematic review, 15 studies reported on the differences in play patterns between the various diagnostic groups and typically developing children in the control groups. Eight of the fifteen studies found that typically developing children were overall more playful than children with ADHD (Alessandri, 1992; Cordier et al., 2010b), CP and/or DCD (Angelin et al., 2018; Okimoto et al., 2000), and developmental delays and other disabilities (Hamm, 2006; Malone, 2009; Pearton et al., 2014; Skinner et al., 2004). Five studies reported on the duration the child remained engaged in play and found that typically developing children spent more time engaged in play compared with children with ADHD (Alessandri, 1992), physical conditions (Cairney et al., 2012; Smyth & Anderson, 2000) and developmental delays and other disabilities (Hestenes & Carroll, 2000; Linn et al., 2000).

Types of play were reported differently across all studies and most were reported as frequency of occurrence of that type of play. Three of the five studies involving children with ADHD reported that children with ADHD engage less in social play as compared with typically developing children (Barnes et al., 2017; Cordier et al., 2010b; Wilkes-Gillan et al., 2016). One study involving children with physical disabilities (Smyth & Anderson, 2000) and another involving developmental delays (Pearton et al., 2014) investigated children's social play. Both studies reported that target children engaged in less social play compared with typically developing children. Compared to typically developing children, children with physical conditions engaged in less gross motor play (Angelin et al., 2018), less pretend play (Hsieh, 2012) and less in play involving games (Smyth & Anderson, 2000). Conversely,

children with developmental delays and other disabilities engaged more in solitary or parallel play (File, 1994; Hestenes & Carroll, 2000) as compared with typically developing children.

In terms of play behaviours, only one of the five studies on ADHD (Alessandri, 1992), three of the five studies on physical conditions (Angelin et al., 2018; Hsieh, 2012; Smyth & Anderson, 2000) and four of the eight studies involving developmental disabilities (File, 1994; Hestenes & Carroll, 2000; Linn et al., 2000; Malone, 2009) reported on play behaviours. Compared to typically developing children, children in the diagnostic groups engaged in more interrupted play (Alessandri, 1992), presented with more onlooker behaviours (Hestenes & Carroll, 2000; Linn et al., 2000) and displayed less complex play (File, 1994; Malone, 2009; Smyth & Anderson, 2000).

Table 2.5: Nuances of Play

Theme	Play descriptors	Typically Developing children	ADHD[a] (5)	Physical (CP[b] & DCD[c] (5)	Developmental delay and other disabilities
Overall playfulness	More playful	▲	▼ (2)	▼ (2)	▼ (4)
Play duration	More time engaged in play	▲	▼ (1)	▼ (2)	▼ (2)
	Time playing alone	▼		▲ (1)	▲ (1)
Types/Forms of play	Solitary or parallel play	▼			▲ (2)
	Constructive rather than functional play	▲	▼ (1)		▼ (2)
	Cooperative play	▲			▼ (2)
	Gross motor play	▲		▼ (1)	▼ (1)
	Sensory play	▼	▲ (1)		
	Pretend or dramatic play	▲		▼ (1)	▼ (2)
	Social play	▲	▼ (3)	▼ (1)	▼ (2)
	Playing games			▼ (1)	
Play Behaviours	Emotional expression	▲		▼ (1)	
	Imagination	▲		▼ (1)	
	Onlooker behaviours	▼		▲ (1)	▲ (1)
	Play interruptions	▼	▲ (1)		▲ (1)
	Passivity during play	▲			▼ (1)
	Organised play	▲		▼ (1)	▼ (2)
	Complex play	▲		▼ (1)	▼ (2)

Notes: [a] Attention Deficit Hyperactivity Disorder; [b] Cerebral Palsy; [c] Developmental Coordination Disorder; ▲ depicts an increase in the play description; ▼depicts a decrease in the play description; values in parenthesis depicts number of studies.

2.5 Discussion

This is the first systematic review to examine how the play profile of children with SHCN is similar or different to that of typically developing children. Although play can be used as a medium to assess children's development, the focus of this review was limited to studies that used play as both an outcome and a medium for intervention for children with SHCN within naturalistic contexts and compared this to typically developing children. Play is a multidimensional and complex construct which is difficult to define (Kent, Cordier, Joosten, Wilkes-Gillan, Bundy, et al., 2020). Thus, the process of focussing the search enabled researchers to compare and contrast the play profiles of children with SHCN to that of typically developing children. A total of eighteen studies met the inclusion criteria. This was surprising, given the high number of studies that investigated play in children and more so the importance of play in everyday doing of children and that play has been used in therapy for a long time (Lynch et al., 2016). However, the number of studies included in this systematic review, is in keeping with number of studies included in other recently published systematic reviews in this field. For example, a systematic review by Kent, Cordier, Joosten, Wilkes-Gillan, Bundy, et al. (2020) included 19 studies and a systematic review by Watts et al. (2014) on play and sensory processing included 8 studies.

Although the search strategy was broad to capture all types of conditions that require SHCN in children, the impact of SHCN on the play of children has only been investigated for the following conditions: ADHD, physical conditions (cerebral palsy and developmental coordination disorder) and developmental delays and other disabilities such as cognitive and speech disorders, Down Syndrome and prenatal alcohol disorders. By defining children with SHCN as children who have or are at risk of physical, developmental, behavioural and emotional difficulties that require more health or related services as compared to typically developing children (McPherson et al., 1998), this review reveals a paucity of research in play for children with several common conditions such as asthma, cystic fibrosis, HIV/AIDS, and cardiovascular diseases. Research on play in children with SHCN is very important as these conditions pose a risk of limitations in performance of daily activities and play. This is particularly pertinent in less economically developed countries where research points to an increase in the prevalence of conditions such as HIV/AIDS and behaviour and/or learning problems.

The main finding of this review is that sixteen of the eighteen studies reported that children diagnosed with SHCN are generally less playful when compared with typically developing children. This finding supports the notion that conditions requiring special health care in children influence a child's developmental trajectory, including play (Sannicandro et al., 2017). Due to illness, children with SHCN are likely to experience more restrictions, fewer opportunities, less access, and less range of ability for play compared to other children (Lynch et al., 2016). Thus, there is need of interventions aimed at promoting play in this population.

Studies reviewed reported play in a variety of ways, which makes it difficult to compare. However, the authors' synthesised the findings against the following four themes: overall playfulness, time engaging in play, types of play, and play behaviours. In terms of types of play, five of the 18 studies reported that children with special health care needs engaged in less social play as compared with typically developing children. Similarly, in a systematic review by Kossyvaki and Papoudi (2016) on play intervention for children with autism in schools, social play was investigated in six of the 14 studies. This could be because most studies used the Test of Playfulness to report on social play. Using standardised measurements allows for uniform reporting, allowing comparison and generalisability to different contexts (Hamm, 2006). This review points to the limited number of measures used in the evaluation of play with eight out of 16 studies using standardised assessments while the other nine studies used a coding system. Most of the coding systems used were specifically designed for that particular study without psychometric details being reported on the validation of the coding system. Using a coding system in the absence of psychometric details has a higher risk of bias as compared with validated tools with sound psychometrics.

Participants were observed playing in environments where they normally play and these include the home, school or at a clinic. The setting was important as research on play in children is best done through observations of children in their naturalistic environment (Lynch et al., 2016). Children tend to play more in familiar environments (Hamm, 2006) and with play things such as toys (Venkatesan, 2014). The environment has a potential to either stimulate or inhibit play as children tend to play in safe and comfortable environments (Cordier et al., 2010b). Findings from this review point to a need to observe the child playing with other children (Bundy et al., 2001; Cordier et al., 2010a), however, there is need for further research on the effects of the presence of a playmate in play.

Although this systematic review gives direction on what research has been done, and points out gaps in areas that need more research focus, most of the studies used small sample sizes making it difficult to generalise the findings.

2.6 Limitations of the study

There are a number of potential limitations of this study. Due to the heterogeneous nature of the studies and outcome measures, it was not possible to conduct a meta-analysis on the similarities and differences in the play of children with SHCN compared with typically developing children. Inclusion was limited to studies published in English only. Three of the authors in this review were also co-authors of three studies included. However, bias was minimised by asking two independent reviewers to screen and select studies to be included in this study. Most studies included in the review were at high risk of bias due to the study design, lack of randomisation and inadequate blinding.

2.7 Conclusion and Implications for future research

Although play is viewed as a childhood occupation that is spontaneous (Cordier et al., 2010a), play in children with SHCN can be limited in frequency, quality and limited in repertoire. This systematic review reveals a paucity of research on play for children with several common chronic conditions such as HIV/AIDS, cancer and cardiovascular diseases. There is a need for more research on the play of children with SHCN; especially in low developed countries were the population of children with SHCN is increasing. Findings from studies included in this review point to children with SHCN being less playful when compared to typically developing children. Furthermore, children with SHCN spent less time engaged in play compared to typically developing children. Future research need to use more rigorous research designs and standardised play outcome measures, as this will allow for comparison and generalisability of findings to other contexts.

Data Availability

The data extraction tables used to support the findings of this study are included within the supplementary information file(s).

Conflicts of Interest

"The author(s) declare(s) that there is no conflict of interest regarding the publication of this paper."

Funding Statement

No funding was provided for this study.

Acknowledgments

A special appreciation goes to Sarah Wilkes Gillan for her contribution during data extraction process.

Supplementary Materials

Supplementary Materials in the form of tables used in the data extraction process have been attached.

2.8 References

1. Alessandri, S. M. 1992. "Attention, play, and social behavior in ADHD preschoolers." *Journal of Abnormal Child Psycholgy* 20 (3): 289-302. https://doi.org/10.1007/BF00916693.
2. Angelin, Anaisa C., Amanda M. P. Sposito, and Luzia I. Pfeifer. 2018. "Influence of functional mobility and manual function on play in preschool children with cerebral palsy." *Hong Kong Journal of Occupational Therapy* 31 (1): 46-53. https://doi.org/10.1177/1569186118783889.
3. Barnes, G., S. Wilkes-Gillan, A. Bundy, and R. Cordier. 2017. "The social play, social skills and parent-child relationships of children with ADHD 12 months following a RCT of a play-based intervention." *Australian Occupational Therapy Journal* 64 (6): 457-465. https://doi.org/10.1111/1440-1630.12417.
4. Berinstein, Stephany, and Lilian Magalhaes. 2009. "A study of the essence of play experience to children living in Zanzibar, Tanzania." *Occupational therapy international* 16 (2): 89-106.
5. Boulton, Michael J., and Peter K. Smith. 1993. "Ethnic, gender partner, and activity preferences in mixed-race schools in the UK: playground observations." In *Children on playgrounds*, edited by Craigh H. Hart, 210-238. Albany: State University of New York Press.
6. Munambah**, N.,** Cordier, R., Speyer, R., Toto, S., & Ramugondo, E. L. (2020). A Systematic Review Comparing the Play Profiles of Children with Special Health Care Needs with Typically Developing Children. *BioMedResearch International*. https://doi.org/10.1155/2020/9582795
7. Bundy, A.C., Lori Nelson, Margaret Metzger, and Kathleen Bingaman. 2001. "Validity and reliability of a test of playfulness." *The Occupational Therapy Journal of Research* 21 (4): 276-292.
8. Bundy, A.C., and G. Skard. 2008. Test of Playfulness. Teoksessa Fazio, L. & Parham, L. Play in Occupational Therapy for Children. USA: Elsevier Inc.
9. Cairney, John, Matthew Y. W. Kwan, John A. Hay, and Brent E. Faught. 2012. "Developmental coordination disorder, gender, and body weight: Examining the impact of participation in active play." *Research in Developmental Disabilities* 33 (5): 1566-1573. https://doi.org/10.1016/j.ridd.2012.02.026.
10. Cattanach, Ann. 2004. *Introduction to Play Therapy*. New York: Routledge.
11. Cordiano, T. J., S. W. Russ, and E. J. Short. 2008. "Development and validation of the Affect in Play Scale-brief rating version (APS-BR)." *Journal of personality assessment* 90 (1): 52.
12. Cordier, Reinie, A.C. Bundy, Clare Hocking, and Stewart Einfeld. 2010a. "Playing with a child with ADHD: A focus on the playmates." *Scandinavian Journal of Occupational Therapy* 17 (3): 191-199.
13. Cordier, Reinie, Anita Bundy, Clare Hocking, and Stewart Einfeld. 2010. "Empathy in the play of children with attention deficit hyperactivity disorder." *OTJR: Occupation, Participation and Health* 30 (3): 122-132.

14. File, Nancy. 1994. "Children's play, teacher-child interactions, and teacher beliefs in integrated early childhood programs." *Early Childhood Research Quarterly* 9 (2): 223-240.
15. Hamm, Ellen M. 2006. "Playfulness and the environmental support of play in children with and without developmental disabilities." *OTJR: Occupation, Participation and Health* 26 (3): 88-96.
16. Hestenes, Linda L., and Deborah E. Carroll. 2000. "The play interactions of young children with and without disabilities: Individual and environmental influences." *Early childhood research quarterly* 15 (2): 229-246.
17. Hsieh, H. C. 2012. "Effectiveness of adaptive pretend play on affective expression and imagination of children with cerebral palsy." *Research in Developmental Disabilities* 33 (6): 1975-83. https://doi.org/10.1016/j.ridd.2012.05.013.
18. Huang, L., G. L. Freed, and K. Dalziel. 2020. "Children With Special Health Care Needs: How Special Are Their Health Care Needs?" *Academic Pediatrics*: 1-7. https://doi.org/https://doi.org/10.1016/j.acap.2020.01.007.
19. Kent, Cally, Reinie Cordier, Annette Joosten, Sarah Wilkes-Gillan, Anita Bundy, and Renée Speyer. 2020. "A systematic review and meta-analysis of interventions to improve play skills in children with Autism Spectrum Disorder." *Review Journal of Autism and Developmental Disorders* 7 (1): 91-118.
20. Khoshali, A. Khajevand, and S. Venkatesan. 2010. "Development of Play Activity Checklist for Childen with Mental Retardation." *Indian Journal of Clinical Psychology* 37 (2): 101-107.
21. Kmet, L. M., R. C. Lee, and L. S. Cook. 2004. *Standard quality assessment criteria for evaluating primary research papers from a variety of fields: Alberta Heritage Foundation for Medical Research.Retreived from http://www. ihe. ca/documents/HTA-FR13. pdf*. Edmonton: Alberta Heritage Foundation for Medical Research (AHFMR.
22. Knox, Susan. 1997. "Development and current use of the Knox Preschool Play Scale." In *Play in occupational therapy for children*, edited by L.D. & Fazio Parham, L.S. , 35-51. St. Louis: Mosby.
23. Kossyvaki, Lila, and Despina Papoudi. 2016. "A review of play interventions for children with autism at school." *International Journal of Disability, Development and Education* 63 (1): 45-63.
24. Landau, Rivka, Riki Amiel-Laviad, Andrea Berger, Naama Atzaba-Poria, and Judith G. Auerbach. 2009. "Parenting of 7-month-old infants at familial risk for ADHD during infant's free play, with restrictions on interaction." *Infant Behavior and Development* 32 (2): 173-182.
25. Liberati, Alessandro, Douglas G. Altman, Jennifer Tetzlaff, Cynthia Mulrow, Peter C. Gøtzsche, John P. A. Ioannidis, Mike Clarke, Philip J. Devereaux, Jos Kleijnen, and David Moher. 2009. "The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration." *PLoS medicine* 6 (7): e1000100.
26. Linn, Margaret Inman, Joan F. Goodman, and Winifred Lloyds Lender. 2000. "Played out? Passive behavior by children with Down syndrome during unstructured play." *Journal of Early Intervention* 23 (4): 264-278.

27. Lynch, Helen, Nóirín Hayes, and Susan Ryan. 2016. "Exploring socio-cultural influences on infant play occupations in Irish home environments." *Journal of occupational science* 23 (3): 352-369.
28. Malone, Michael. 2009. "Patterns of Home-and Classroom-based Toy Play of Preschoolers With and Without Intellectual Disabilities." *International Journal of Disability, Development and Education* 56 (4): 333-347.
29. Mattson, Gerri, and Dennis Z. Kuo. 2019. "Psychosocial factors in children and youth with special health care needs and their families." *Pediatrics* 143 (1): 1-15. https://doi.org/https://doi.org/10.1542/peds.2018-3171.
30. McPherson, Merle, Polly Arango, Harriette Fox, Cassie Lauver, Margaret McManus, Paul W. Newacheck, James M. Perrin, Jack P. Shonkoff, and Bonnie Strickland. 1998. "A new definition of children with special health care needs." *Pediatrics* 102 (1): 137-139. https://doi.org/10.1542/peds.102.1.137.
31. Miller, Elissa, and Heather Kuhaneck. 2008. "Children's perceptions of play experiences and play preferences: A qualitative study." *American Journal of Occupational Therapy* 62 (4): 407-415.
32. Miller, Lauren S, Meng Wu, Anne M. Schettine, and Lindsay W. Cogan. 2018. "Identifying Children with Special Health Care Needs Using Medicaid Data in New York State Medicaid Managed Care." *Health services research* 53 (6): 4157-4177.
33. Moher, David, Alessandro Liberati, Jennifer Tetzlaff, and Douglas G. Altman. 2009. "Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement." *Annals of internal medicine* 151 (4): 264-269.
34. Nabors, Laura. 1995. "Attitudes, friendship ratings, and behaviors for typically developing preschoolers interacting with peers with disabilities." biennial meeting of the Society for Research in Child Development, Indianapolis, 1995.
35. National Health and Medical Research Council. 2000. "Guide to the Development, Implementation and Evaluation of Clinical Practice Guidelines." *Canberra: National Health and Medical Research Council* 88.
36. Okimoto, Ann Mari, Anita Bundy, and Jodie Hanzlik. 2000. "Playfulness in children with and without disability: Measurement and intervention." *American Journal of Occupational Therapy* 54 (1): 73-82.
37. Parten, Mildred B. 1933. "Social play among preschool children." *The Journal of Abnormal and Social Psychology* 28 (2): 136.
38. Pearton, Jordan Louise, Elelwani Ramugondo, Lizahn Cloete, and Reinie Cordier. 2014. "Playfulness and prenatal alcohol exposure: A comparative study." *Australian Occupational Therapy Journal* 61 (4): 259-267. https://doi.org/10.1111/1440-1630.12118.
39. Ramugondo, Elelwani L. 2012. "Intergenerational play within family: The case for occupational consciousness." *Journal of Occupational Science* 19 (4): 326-340.
40. Sannicandro, Thomas, Susan L. Parish, Esther Son, and Robyn M. Powell. 2017. "Health care changes for children with special health care needs, 2005–2011." *Maternal and child health journal* 21 (3): 524-530. https://doi.org/10.1007/s10995-016-2136-4.
41. Skard, Geva, and Anita C. Bundy. 2008. "Test of playfulness." In *Play in occupational therapy for children*, 71-93. Elsevier.

42. Skinner, Martie L., Virginia Buysse, and Donald B. Bailey. 2004. "Effects of age and developmental status of partners on play of preschoolers with disabilities." *Journal of Early Intervention* 26 (3): 194-203.
43. Smyth, Mary M., and Heather I. Anderson. 2000. "Coping with clumsiness in the school playground: Social and physical play in children with coordination impairments." *British Journal of Developmental Psychology* 18 (3): 389-413.
44. Sterman, Julia, Geraldine Naughton, Elspeth Froude, Michelle Villeneuve, Kassia Beetham, Shirley Wyver, and Anita Bundy. 2016. "Outdoor play decisions by caregivers of children with disabilities: A systematic review of qualitative studies." *Journal of Developmental and Physical Disabilities* 28 (6): 931-957.
45. Todd, Brenda K., Rico A. Fischer, Steven Di Costa, Amanda Roestorf, Kate Harbour, Paul Hardiman, and John A. Barry. 2018. "Sex differences in children's toy preferences: A systematic review, meta-regression, and meta-analysis." *Infant and Child Development* 27 (2): e2064.
46. Van Dyck, Peter C., Michael D. Kogan, Merle G. McPherson, Gloria R. Weissman, and Paul W. Newacheck. 2004. "Prevalence and characteristics of children with special health care needs." *Archives of pediatrics & adolescent medicine* 158 (9): 884-890. https://doi.org/10.1001/archpedi.158.9.884.
47. Vandenberg, Brian, and Gary Kielhofner. 1982. "Play in evolution, culture, and individual adaptation: Implications for therapy." *American Journal of Occupational Therapy* 36 (1): 20-28.
48. Venkatesan, S, and Nimisha Ravindran. 2012. "Play behaviors and activities in siblings of children with developmental disabilities." *Journal of Indian Academy of Applied Psychology* 38 (1): 74-83.
49. Venkatesan, Srinivasan. 2014. "Availability of toys for children with developmental disabilities." *Journal of Disability Management and Special Education* 4 (1): 58-70.
50. Watts, Tara, Karen Stagnitti, and Ted Brown. 2014. "Relationship between play and sensory processing: A systematic review." *American Journal of Occupational Therapy* 68 (2): e37-e46.
51. Wijlaars, Linda P. M. M., Ruth Gilbert, and Pia Hardelid. 2016. "Chronic conditions in children and young people: learning from administrative data." *Archives of disease in childhood* 101 (10): 881-885. https://adc.bmj.com/content/archdischild/101/10/881.full.pdf.
52. Wilkes-Gillan, Sarah, A.C.. Bundy, Reinie Cordier, Michelle Lincoln, and Yu-Wei Chen. 2016. "A randomised controlled trial of a play-based intervention to improve the social play skills of children with attention deficit hyperactivity disorder (ADHD)." *PLOS one* 11 (8): e0160558. https://doi.org/10.1371/journal.pone.0160558.

3 CHAPTER 3: Play profiles of children with HIV/AIDS

3.1 Introduction

Chapter 3 presents findings on the play profiles of children with HIV/Aids. Due to the paucity of literature on the play of children with HIV/Aids as described in chapter 2, this chapter shares how the researcher deepened her understanding of the play of children with HIV/Aids by observing the play interactions between children with HIV/Aids and typically developing playmates and comparing those play patterns against age and gender matched typically developing children from similar low resourced contexts. The study design, target population including the inclusion and exclusion criteria is explained. Data collection, analysis and findings are also shared. The chapter concludes by presenting the key points for occupational therapy.

The chapter is a journal manuscript on the similarities and/or differences in the play profiles of children with HIV/Aids compared to typically developing. The chapter was accepted for publication in the Australian Journal of Occupational Therapy on 31 October 2020. It is published as:

> Munambah, N., Cordier, R., Chiwaridzo, M., & Ramugondo, E. L. (2020) Play profiles of children with HIV/Aids: A comparative study, *Australian Occupational Therapy Journal*, 1-13. doi: 10.1111/1440-1630.12712

The article is presented as Microsoft Word document and has been formatted according to the Australian Occupational Therapy Journal. A list of references for this chapter is presented at the end of the chapter.

3.2 Abstract

Introduction

Despite play being widely used in occupational therapy practice as a means and ends in intervention, no research has explored how the play of children with HIV/Aids is affected. Therefore, the specific processes through which play can be used in therapy with children with HIV/Aids remains underexplored, especially in low resourced settings. This study aims to compare the level of playfulness of children with HIV/Aids to that of age and gender matched typically developing children living in the same low resourced community.

Methods: The Test of Playfulness (ToP) was used to examine the differences and similarities of play between children aged 4-7 years who are typically developing children (n=52) and children with HIV/Aids who receive antiretroviral treatment (n=44). Each child was video recorded playing with a familiar playmate both indoors and outdoors. The videos were scored by two independent raters who were blinded to all aspects of the study. Scores were subjected to Rasch analysis to calculate interval level measure scores. Independent *t*-tests were used to compare differences between the means of the groups.

Results:

Typically developing children scored significantly higher when playing outdoors, as compared to children with HIV [t (94) =3.57, $p = 0.001$]. There was no significant difference between mean measure scores for indoor play when comparing typically developing children and children with HIV. Children who are HIV positive scored significantly lower than typically developing children on items related to the ability to suspend reality and framing in both indoor and outdoor environments.

Conclusions: This study provides insight on the play profiles of children with HIV/Aids from a low resourced setting, highlighting play deficits and areas interventions could target. Occupational therapy can play a significant role in promoting playfulness in children with HIV/Aids.

Key Words: Children, Play, Playfulness, HIV/Aids,

3.3 Background Information

More than three decades after it was first diagnosed, HIV/Aids remains a major global health problem, despite global solidarity in response to the epidemic (Demmer, 2011). Until recently, paediatric HIV treatments focused on preventing mortality (Potterton et al., 2016). However, with the advent of Antiretroviral therapy (ART), improvements in health and life expectancy has resulted in HIV/Aids changing from being an incurable disease to a chronic disease (Kandawasvika et al., 2015). Subsequently, the efforts of saving children's lives need to be complimented by availing opportunities for children to live meaningful lives through interventions that mitigate the impact of HIV/Aids on children.

Children living with HIV/Aids face life long risk of concomitant illnesses (Skeen et al., 2017) and are at high risk of developing mild to severe impairments in all spheres of development (Potterton et al., 2016). A study by Mlambo et al. (2017) revealed that children infected with HIV/Aids are likely to have neurocognitive impairments that will affect their everyday activities, such as schooling. Furthermore, children with HIV/Aids are likely to experience stigma, trauma and low mood (Demmer, 2011). Research has shown that most people living with HIV/Aids in the Sub-Saharan Africa live in poverty (Masanjala, 2007). In Zimbabwe, the situation is precipitated by the socio-economic challenges and migration to neighbouring countries. In most rural settings, everyday doings of both children and adults are mainly centred on survival (Campbell et al., 2013). Economic factors that threaten survival, combined with cultural and relational practices are likely to limit engagement and participation in meaningful occupations, such as play. As a result of a combination of these factors, many children with HIV/Aids are likely to experience deficits in their play and other areas of child development. Therefore, to limit the impact of HIV/Aids on the lives of children, research recommends screening, early identification, comprehensive assessment and interventions for this population (Potterton et al., 2016; Skeen et al., 2017).

Play is the main childhood occupation that allows children to learn and develop fundamental motor, cognitive and socio-emotional skills (Lynch et al., 2016). Through play, children learn survival skills, build resilience to deal with adverse life events and develop self-efficacy (Milteer & Ginsburg, 2012). Play provides a window to a child's development (Lynch & Moore, 2016), thus occupational therapists have used it as both a means and an outcome to intervention. Over the years, occupational therapists used play as a means to understand and improve the functional outcomes of children with a broad range of disabilities. Inability to

engage in play well with others can lead to children developing a negative self-concept and becoming socially isolated (Pearton et al., 2014). Recent developments on the centrality of occupation in occupational therapy practice have seen play also being viewed as an outcome measure (Cordier et al., 2010b). Occupational therapists are positioned to enable play in children with limitations. The process of promoting play in children extends beyond teaching play skills or practising play activities in therapy clinics to include the design of context-focused interventions that focus on play, playfulness and participation in play by collating a detailed profile of all aspects of play in children (Lynch & Moore, 2016). A detailed play profile, in turn, is important in understanding children's play deficits and helps in formulating evidence-informed interventions (Halfon, 2017).

Skard and Bundy (2008, p. 71) define play as "…a transaction with the environment that is intrinsically motivated, internally controlled and free from the constraints of reality." Play manifests itself as playfulness in children (Bundy, 1997; Cordier et al., 2010b). Playfulness is the predisposition to play, which remains constant overtime and is related to a child's ability to cope in later life (Skard & Bundy, 2008). Based on Bundy's model of playfulness (Bundy, 1997), the construct of playfulness is comprised of the following four elements: intrinsic motivation, internal control, freedom to suspend reality and framing. Playfulness offers researchers and clinicians an opportunity to focus on a child's quality of play, adaptability and coping mechanisms, regardless of ability (Hamm, 2006). The terms play and playfulness have been used interchangeably in literature. For the purpose of this study, the term play profiles will be used henceforth where appropriate.

Even though the benefits of play and being playful has been widely explored (Halfon et al., 2016), the play profiles of children with HIV/Aids is likely to be affected due to neuro-cognitive deficits and developmental delays associated with HIV/Aids (Potterton et al., 2016), and factors in the environment like stigma and poverty. Broadly, there is a paucity of literature on children's play in this context. One of the few studies on the caring occupation for children with HIV/Aids in Zimbabwe reported that due to fear of stigma, guiltiness and self-blame, caregivers were not willing to share their caregiving role with anyone instead their everyday doings were centred on care and protecting the children from stigma and possibilities of further harm (Munambah, Gretschel, et al., 2020). Developing a better understanding of the play profile would improve the use of play as both an intervention outcome, as well as a medium for delivering intervention. This study aims to compare the

play profiles of children with HIV/Aids aged 4-7 years to that of age and gender matched typically developing children living in the same low resourced community. Play profiles vary across age groups and the type and nature of play profile changes as the child matures (Cordier, Bundy, Hocking, & Einfeld, 2010a). Similarly in low resourced settings, play is often incorporated into daily chores, children of the same age groups often play together. However, typically developing children aged 4-7 years engage in similar types of play (Dadson et al., 2020), thus enabling comparison. Creating an understanding of the play profile of children with HIV/Aids would produce building blocks towards developing play-based interventions for this population. Thus, this study seeks to address the following objectives:

1. To determine if there is a difference in overall play profiles of children with HIV/AIDS versus typically developing children;
2. To compare the play profiles (indoor versus outdoor) of children with HIV against typically developing children; and
3. To determine if there is a difference in individual item scores of ToP categories between children with HIV versus typically developing children.

3.4 Methodology

Ethical approval was obtained from the University of Cape Town (HREC number 640/2017). In Zimbabwe where data was collected, ethical approvals were obtained from Medical Research Council of Zimbabwe (MRCZ ref no A/2364) and Joint Research and Ethics Committee (JREC ref no.163/18).

3.4.1 *Study Design:*

This study is a quantitative matched control, comparative study.

3.4.2 *Research setting:*

Children with HIV/Aids and their caregivers were recruited from two major referral hospitals in Zimbabwe. Almost all the children with HIV recruited for this study were from high density urban settings and attended government schools. Typically developing children were recruited from two government primary schools. Globally, Zimbabwe is ranked as a low income country with a gross national income per capita of less than or equal to US$1005

(Bank, 2013; McIndoe-Calder et al., 2019). Participants were drawn from urban settings with the vast majority living in poverty. A study by Manjengwa et al. (2016) revealed that Zimbabwe experiences urban poverty and the major determinants of poverty were large sized family, low education level of the household head, and lack of income from permanent employment. All participants in our study were drawn from within this context of being a low resourced setting (Manjengwa et al., 2016).

3.4.3 *Participants and recruitment*

The study involved 98 children, aged 4-7 years living in low resourced settings. Data from two children were excluded from data analysis because they were identified to be outliers as evidenced by poor person fit statistics according to the Rasch model, thus reducing the total sample from 98 to 96 children. Children involved in this study were divided into two groups. The composition of groups was as follows: group 1 involved 44 dyads (44 children with HIV/Aids playing with 44 typically developing children) and group 2 involved 26 dyads (26 typically developing children playing with 26 typically developing children). The data from the 44 children with HIV/Aids in group 1 and the 52 typically developing children in group 2 were included in the analysis. Intergroup frequency matching based on age and gender was used to match children with HIV/Aids in group one to typically developing children in group two. Playmates of children who are HIV positive in group one and children in group two were not infected with HIV as reported by their caregivers and the health screening from the nurse. All playmate pairs were familiar with one another. Motor skills are important in facilitating play performance (Harkness & Bundy, 2001). As such, only the domain of 'getting around' of the World Health Organization Disability Assessment Schedule (WHODAS) was used as a screen questionnaire to ensure children involved in the study were able to stand up from sitting, to stand for long periods (> 30 minutes) and moving around the home among other things. None of the children involved in this study had difficulty in performing two or more of the five items in the domain: 'getting around' of WHODAS questionnaire.

3.4.3.1 Children with HIV/Aids group

Comprised of 44 children who were diagnosed by doctors and undergoing medical treatment. These children were recruited from two main central hospitals in Zimbabwe at the outpatient clinics, as they attended their monthly review meetings with doctors. Children who had physical disabilities that affect engagement and participation in play were excluded from the study. To reduce research fatigue, children participating in other studies were excluded from

this study. Children who had attended play-based interventions were also excluded from the study, so as to reduce the risk of contamination due to being exposed to a play-based intervention.

3.4.3.2 Typically developing children group

The typically developing children group comprised of 52 children who had not been diagnosed of HIV by a medical doctor as reported by the caregivers and from the health assessment by the nurse. The children were recruited from two public government primary schools. One school is located in a peri-urban area and other school is in high density suburb of Harare. This group was matched by age and gender to children with HIV/Aids. In this study a typically developing child was defined as a child who is not HIV positive, based on medical records and from caregiver report. Also, the child passed a health assessment performed by a nurse and no concerns about development had been raised by the teacher or health professional. Children with any other diagnosis that might affect play or children with physical disabilities that affect engagement and participation in play and those involved in another research running parallel to this study were excluded from the study.

3.4.3.3 The playmate

In this study, a playmate has been defined as a child well known to the target child, whom they choose to play with. A play dyad refers to these two children (target child with chronic illness and his/her playmate) playing together. This study involved observations and video recording of children playing either in a playroom at the University of Zimbabwe, Department of Rehabilitation or at school, as well as playing in the home (familiar) environment. Thus, a child living with HIV/Aids or a typically developing child, who meets the inclusion criteria, and has been selected for this study, would play with another child who will be referred to as the playmate.

3.4.4 *Recruitment Procedure*

Recruitment for children with HIV/Aids was done at the hospitals and typically developing children were recruited from two schools. At the hospital, caregivers of children with HIV/Aids were invited to participate in the study via a recruitment pamphlet which provided a brief explanation about the study. Those who expressed interest to participate were invited to a private clinic room, where they were provided with a detailed explanation using the participant information letter. Those caregivers willing to take part in the study were asked to sign informed consent and were possible, children also signed assent forms. Care was taken to ensure caregivers had enough time to make an informed decision. A nurse then carried out a health assessment and reviewed the road to health card for each child. Recruitment of

typically developing children at schools followed the schools' formal communication procedures. Participant information letters about the study were sent out to the caregivers and those interested in the study were invited to attend a meeting at the school. A detailed explanation of the research was given before caregivers were asked to provide signed consent to participate in the study and, where possible, children also signed assent forms as well.

All the children who meet the inclusion criteria and their caregivers consented to participation in this study were screened for physical challenges that might affect participation in play. The 'Getting around' domain on the WHODAS questionnaire was used to screen children with physical challenges. As part of the recruitment process; a health assessment by a nurse was carried out on all children who participated in the study. The health assessment included observations, the measurement of vital signs and self-reported symptoms. The nurse also reviewed the road to health card for each of the children involved in this study. The road to health card is used in primary health care as a way of monitoring a child's health. Caregivers were also asked about the health of their child. Following screening, none of children with HIV/Aids presented with co-morbid conditions or physical challenges that may have influenced their play.

3.4.5 *Instruments*

3.4.5.1 Socio-demographics Questionnaire:

A questionnaire collecting demographic data of the caregiver and the child was developed by the researcher in line with study objectives. The questionnaire was given to a panel of experts to review the questionnaire for relevance, comprehensiveness and comprehensibility. The panel included four experienced occupational therapists, a researcher with experience in working with children, and a local (Zimbabwean) experienced researcher. The questionnaire was refined through a pilot study. Variables on demographic information such as age, sex and condition of the child, as well as demographic information of the caregiver were covered. The questionnaire was also used to collect information on the play history of the child.

3.4.5.2 Test of Playfulness (ToP)

An observational tool called the Test of Playfulness (Version 4) (see Appendix R), which was designed to evaluate playfulness in children aged 6 months to 18 years, was used in this study (Skard & Bundy, 2008). The ToP measures playfulness without giving penalties to motor deficiencies, thus allowing for comparisons of playfulness across children (Hamm, 2006).

The ToP comprises of 29 items that are rated on a four-point scale (0-3) and scores reflect the extent (amount of time), intensity (degree of participation) and skill (ease of performance) relative to the play behaviours expressed by the child (Skard & Bundy, 2008). Social play items require an interaction between two or more players for the item to be scored (Wilkes-Gillan et al., 2014). Nine out of the 29 items of the ToP reflect social play and a list of these can be found in Supplementary Table 3.6. The ToP has been used with different clinical populations and across different environments (Rigby & Gaik, 2007) and has been found to be a stable assessment for play. The validity and reliability of the ToP has been established in children with and without disabilities (Bundy et al., 2001). The ToP has evidence for excellent inter-rater reliability (data from 96% of raters fit the expectations of the Rasch model) and construct validity (data from 93% of items and 98% of people fit Rasch expectations) (Harkness & Bundy, 2001).

3.4.5.3 The Test of Environmental Supportiveness (TOES)

The TOES assesses the extent to which elements of a particular environment support an individual child's play (Bronson & Bundy, 2001). The elements of the environment could either be human (the caregivers, playmates) or non-human (objects and play spaces). The TOES is a 17 item observational measure which takes 15 to 20 minutes to administer (Harkness & Bundy, 2001). The reliability coefficient for the TOES, associated with the separation value (equivalent to Cronbach's alpha) was 0.77 (Bundy et al., 2001). In this study the TOES was used to assess the extent to which the human and non-human aspect of the environment supported or interfered with the child's play.

3.4.5.4 World Health Organization Disability Assessment Schedule (WHODAS) version 2

The WHODAS Version 2 is an assessment of disability based on the conceptual framework of the International Classification of Functioning, Disability, and Health (ICF) (Garin et al., 2010). It provides a global measure of disability and has seven domains: Understanding and Communicating (6 items), Getting around (5 items), Self-care (4 items), Getting along with others (5 items), Life activities: household (4 items), Life activities: work/school (4 items), and Participation in society (8 items). In this study only the domain of getting around was used to screen the children for difficulty in moving around. The reliability coefficient Cronbach's alpha was above 0.7 for all WHODAS-2 sub-scales (Garin et al., 2010).

3.4.6 *Procedure of data collection*

The first author and the research assistants involved in data collection were all qualified health professionals practising in Zimbabwe and were familiar with the language and cultural nuances within that context. Prior to data collection, the research team had training on data collection procedures, child policy, cultural sensitivity and ethics in research and signed confidentiality agreement forms. Recruitment at the hospital was done by the first author with the help of the nurse. The nurse works at outpatient clinic and has experience in research. Two research assistants blinded of the HIV status of the participants were involved in data collection. Caregivers provided informed consent on behalf of their children through signing informed consent forms provided. Children who met the inclusion criteria together with their playmates were invited to take part in this study and, if able, signed assent forms that were also co-signed by the caregivers. Caregivers were asked to fill in a socio-demographic questionnaire with the help of the researcher. Data collection involved observing each participant and his/her playmate playing in both an indoor and outdoor play environments.

The *indoor play environment* was a room with standard local toys. Children with HIV/Aids and their playmates were observed playing in a room with toys at the clinic they regularly attended and the control group was observed playing in a room, equivalent in size to the clinic room, with toys at the respective schools the children attended. The ToP requires no special equipment (Bundy et al., 2001). However, to motivate the children to engage in free play, a box of standard toys for children aged 4-7 years, bought from a local toy shop, was provided to children both at the clinic and at the schools. The toys were carefully selected to make sure they were culturally sensitive and they catered for gender differences. The same toys were used throughout the study and included dolls, cars, building blocks, boxes, masks, sand pit, variety of animals, balls of different sizes, dress up clothes, jingles and musical drums, to name but a few. The children were allowed to choose play materials and activities. A digital camera was mounted in the room in such a way that it did not obstruct the children's play and was used to video record all the play sessions. Also, an unobtrusive observer was present in the play room and did not interfere with the play unless a child was in danger. Each play dyad was given 15 minutes to adjust to the playroom environment before recording started. The researcher adhered to the ToP procedures which states that children should be observed for 15 minutes while playing (Bundy et al., 2001).

The *outdoor play environment* was at the children's homes. All the children who participated in this study came from similar socio-demographic backgrounds and as such, in practical terms, had the same access to community spaces. None of the children involved in this study lived in apartments. For outdoor play, both children with and without HIV/Aids were asked to play in their yard with the toys they would normally play with. Data were collected in different yet equivalent settings. This was to ensure familiarity with the play environments and convenience for the families (Cordier et al., 2010a). The researchers made sure that play environments used to score the ToPs were ones in which the child felt physically and emotionally safe in order to increase chances of spontaneous and intrinsically motivated play behaviour to occur (Bundy 2004). The test of environmental supportiveness (TOES) was used to assesses the extent to which human and non-human aspect of the environment support an individual child's play (Bundy et al., 2001). The TOES operationalises the ways in which the following four aspects influence players motivation to play: playmates, objects, play space, and the sensory environment (Skard & Bundy, 2008). The same procedure was followed for data collection in the home environment as was done in the playroom at the clinic and the school.

3.4.7 *Data Analysis*

The recordings were given to two independent raters who were trained and calibrated on the use of the ToP. Calibration ensured consistency of the raters by comparing their scores to hundreds of other raters in the larger ToP sample (N > 3000 observations) and goodness of fit statistics derived from the calibration data were within acceptable range. In order to minimise bias, the raters were blinded for the purposes of the study and they did not participate in any other aspect of the study. The raters scored the performance of the children on the ToP score sheet. The raw ToP scores were subjected to Rasch analysis using Winsteps program (version 3.70.1) to convert children's ToP raw ordinal scores (0, 1, 2, 3) into interval level measure scores and generate total measure score for each child. All the blinded raters' were calibrated and found to be reliable with fit statistics within acceptable ranges (MnSq < 1.4; standardised value < 2) (Bond & Fox, 2007). The resulting measure scores were entered into SPSS version 22 and independent *t*-test was used to compare differences between the means of the groups. Analysis of the individual ToP items (ordinal level) was conducted using the Mann Whitney U test in cases where there was no data dependency (e.g., comparing the play between different children) and the Wilcoxon Signed Ranks test was used where there was data dependency (e.g., comparing indoor and outdoor data for the same child).

3.5 Results

3.5.1 *Participants:*

The study involved 98 children. However, person measure scores for two children were identified to have poor fit statistics according to the Rasch model and their data were excluded from further analysis. Fifty two (54.2%) were typically developing children and 44 (45.8%) were children with HIV and received antiretroviral treatment.

Table 3.1 summarises the demographics of the children. Most children (22; 50.0%) with HIV and 44 (84.6%) control were enrolled in grades 1 and 2. There were 4 (9.1%) children with HIV who were not attending school, as compared with none in the control group. Most children with HIV (40; 91%) were on first line of antiretroviral drugs and the reported comorbid conditions were Tuberculosis, Heart problem and Malnutrition.

Table 3.1: Demographics of the children

Item	Description	Typically Developing Children (n=52)	HIV positive Children (n=44)
Mean Age†		7.1 (SD=1.49)	6.8 (SD=1.49)
Gender‡	Female	20 (38.5%)	23 (52.3%)
	Male	32 (61.5%)	21 (47.7%)
Grade in school	Not in school	0	4 (9.1%)
	ECD	4 (7.7%)	12 (27.3%)
	Grade 1and 2	44 (84.6%)	22 (50.0%)
	Grade 3 and 4	4 (7.7%)	6 (13.6%)
Antiretroviral Therapy	First line	-	40 (90.9%)
	Second line	-	4 (9.1%)
Co-morbid conditions	Tuberculosis	-	2 (4.5%)
	Heart problem	-	2 (4.5%)
	Malnutrition	-	1
Main Person child plays with	Older child	8 (15.4%)	10 (22.7%)
	Same age child	19 (36.5%)	21 (47.7%)
	Younger child	25 (48.1%)	11 (25.0%)
	Alone	0	2 (4.5%)
Most common play spaces	Outdoor – Playgrounds§	21 (40.4%)	4 (9.1%)
	Outdoor – streets	5 (9.6%)	3 (6.8%)
	Outdoor – around the yard	22 (42.3%)	32 (72.7%)
	Inside house	4 (7.7%)	5 (11.4%)

Note. †There was no significant difference in the mean age of typically developing children and HIV+ children (t = 1.26, p = 0,209). ‡There was no significant gender difference between typically developing and HIV+ children (X^2= 1.84, p = 0.18). §Playgrounds – these are outdoor play spaces outside the proximity of the house where children play. This includes school grounds, open spaces where children play within the community.

Half of children with HIV (22; 50%) played mostly with children of the same age, whereas proportionally less typically developing children (22; 42%) mostly played with younger children. Based on the sociodemographic questionnaire that caregivers completed, compared

with typically developing children (22; 42.3%), a significantly higher proportion of children with HIV (32; 72.7%) played mostly in their yards when they played outdoors. Conversely, a significantly higher proportion of typically developing children (21; 40.4%) played in designated playgrounds within their communities compared with children who are HIV positive (4, 9.1%; $X^2 = 9.81$, $p = 0.0017$). This indicates that children with HIV were more likely to be restricted in accessing community play spaces, compared with typically developing children.

3.5.2 *Demographics of the responding caregivers:*

Caregivers of children with HIV were mostly informally employed (25; 56.8%) compared with caregivers of typically developing children (22; 42.3%). A significantly larger proportion of caregivers of HIV positive children (26; 59.0%) reported spending more than 20 hours per week with their child, compared with caregivers of typically developing children (15, 28.8%; $X^2 = 8.05$ $p = 0.0045$). See Table 3.2 for demographics of the responding caregivers.

Table 3.2: Demographics of the responding caregiver

Demographic variables	**Description**	**Typically Developing Children (n=52)**	**HIV positive (n=44)**
Mean Age		38.3 (SD ±7.83)	39.8 (SD ±9.18)
Gender	Female	41 (78.8%)	39 (88.6%)
	Male	9 (17.3%)	4 (9.1%)
Level of Education	Primary	8 (15.4%)	10 (22.7%)
	Secondary	36 (69.2%)	34 (77.3%)
	Tertiary	5 (9.6%)	-
Relationship of caregiver to child	Biological parent	46 (88.5%)	35 (80%)
	Aunt	2 (3.8%)	2 (4.5%)
	Grand Parent	4 (7.8%)	5 (11.4%)
	Uncle	-	1 (2.3%)
	Foster Parent	-	1 (2.3%)
Mean number under caregiver's care		2.8 (SD 1.41)	2.8 (SD 1.74)
Employment Status	Informal employment†	22 (42.3%)	25 (56.8%)
	Full-time	16 (30.8%)	2 (4.5%)
	Part-time	4 (7.7%)	3 (6.8%)
	Not employed	10 (19.2%)	14 (31.8%)
Time caregiver spent with child per week	Less than or equal to 7 hours	7 (13.5%)	4 (9.1%)
	8-20 hours	30 (57.7%)	14 (31.8%)
	More than 20 hours	15 (28.8%)	26 (59.0%)

Note. †informal employment – includes workers who are self-employed, or who work for those who are self-employed. In most cases are not on payrolls, and thus are not taxed. Most common informal employment includes backyard manufacturing industries, trading and vending.

3.5.3 *Play profiles*

The overall ToP mean measure score for outdoor play was 49.5 (SD = 22.74) and slightly lower for indoor play (M = 47.3; SD = 22.63). Using an independent sample *t*-test, there was

no significant difference between mean measure scores for indoor play when comparing typically developing children and children with HIV. However, as shown in
Figure 3.1, children with HIV were less playful outdoors as compared to typically developing children ($t(94) = 3.57$, $p = 0.001$).

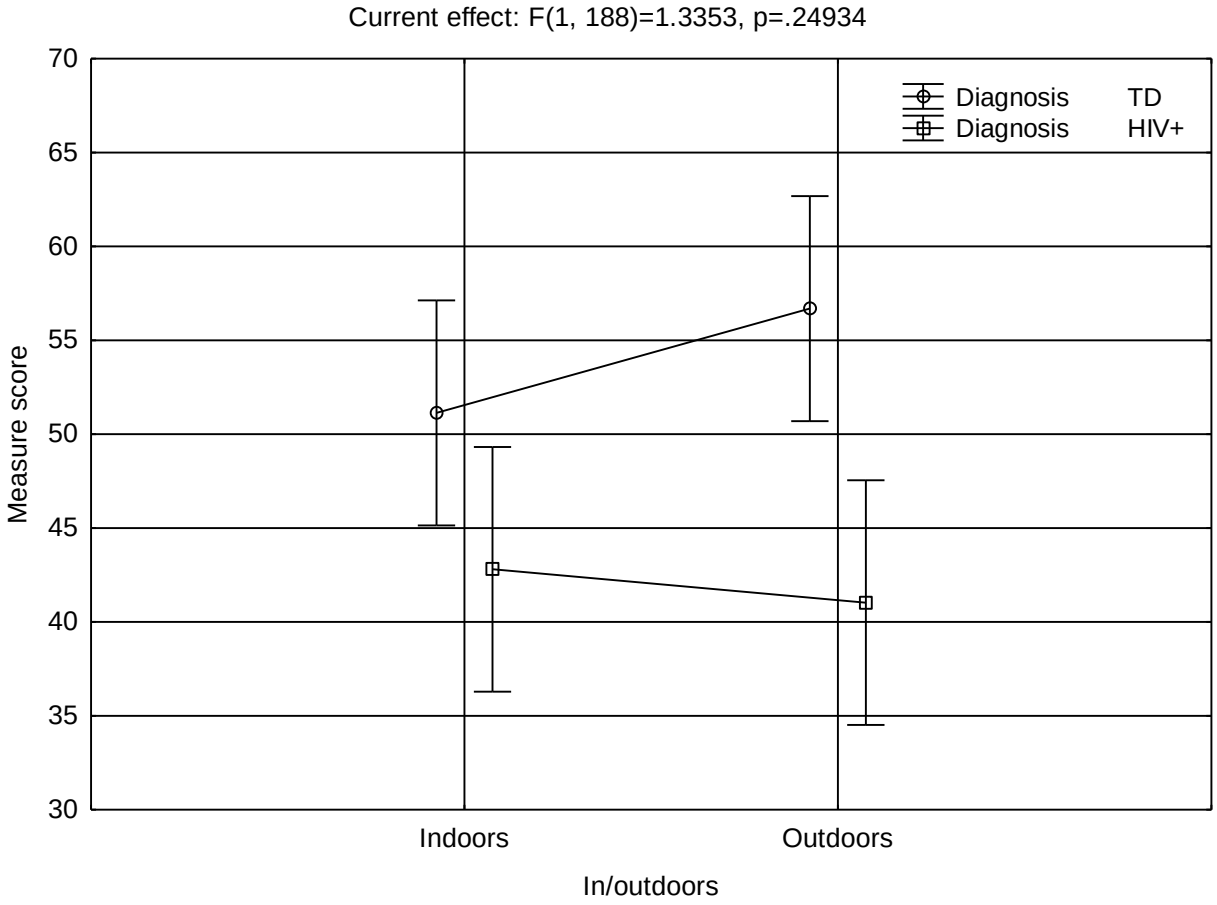


Figure 3.1: Mean outdoor and indoor scores by diagnosis

When comparing the mean ToP measure scores for typically developing children for outdoor play against HIV positive children's indoor play, the results showed that typically developing children scored significantly higher when playing outdoor than HIV positive children playing indoor ($t(94) = 3.02$; $p = 0.003$). Furthermore, the indoor play of typically developing children was also significantly higher than the mean ToP measure scores for outdoor play for HIV positive children (t (94) = 2.31; $p = 0.02$). We explored the relationship between employment status of caregivers and children's ToP measure scores and found that there was no relationship.

3.5.4 *Test of Playfulness item scores:*

For item level ToP scores, Wilcoxon Signed-Ranks tests indicated that the extent of being involved in the process of play was higher when playing outdoors (mean rank = 3.0) as compared to when playing indoors (mean rank = 2.0; $Z = 2.35$; $p = 0.02$). Also, the extent of playing with others was higher when playing outdoors (Mean rank = 3.0) as compared to when playing indoors (mean rank = 2.0; $Z = 2.41$; $p = 0.02$). See Supplementary Table 3.3 for more detail. Although there were no significant differences between the overall mean measure indoor ToP scores of children with HIV and typically developing children (see Figure 1), an item level analysis using the Mann Whitney U test for indoor ToP scores showed significant differences for seven items (see Supplementary Table 3.4).

Table 3.3: Comparing indoor vs outdoor for ToP scores for HIV+ group sub-item analysis

		Indoor		Outdoors		Wilcoxon Matched Pairs Test (Person measure scores in Person measure scores complete data spss HIV+) Marked tests are significant at p <.05000			
	Pair of Variables	Median	IQR	Median	IQR	Valid N	T	Z	p-value
1	Extent of being engaged	2.0	2.0	2.0	2.0	40	389.50	0.28	0.783
2	Intensity of being engaged	2.0	2.0	2.0	2.0	29	195.00	0.49	0.627
3	Skill of being engaged	2.0	2.0	2.0	2.0	30	225.00	0.15	0.877
4	Extent of deciding what to do	2.0	2.0	2.0	2.0	26	112.50	1.60	0.110
5	Intensity of interacting with objects	2.0	2.0	2.0	2.0	21	77.00	1.34	0.181
6	Intensity of persistence	2.0	2.0	2.0	3.0	24	132.00	0.51	0.607
7	Skill of modifying task requirements	2.0	2.0	2.0	3.0	27	130.50	1.41	0.160
8	Extent of being involved in the process	2.0	2.0	2.0	3.0	31	128.00	2.35	*0.019
9	Extent of pretends	2.0	3.0	2.0	2.0	34	297.00	0.01	0.993
10	Skill of pretending	2.0	2.0	2.0	2.0	32	231.00	0.62	0.537
11	Extent of using people and objects unconventionally	2.0	3.0	2.0	2.0	30	217.00	0.32	0.750
12	Skill of using people and objects unconventionally	2.0	3.0	2.0	3.0	38	312.00	0.85	0.396
13	Skill of negotiating needs	2.0	2.0	2.0	3.0	46	474.50	0.72	0.471
14	Extend of playing with others	2.0	3.0	2.0	3.0	56	502.00	2.41	*0.017
15	Intensity of playing with others	2.0	3.0	2.0	3.0	36	210.00	1.93	0.053
16	Skill of playing with others	2.0	3.0	2.0	2.0	37	296.00	0.84	0.402
17	Skill of supporting the play of others	2.0	3.0	2.0	2.0	41	380.50	0.65	0.517
18	Skill of initiating new activities	2.0	3.0	2.0	3.0	44	465.00	0.35	0.726
19	Skill of sharing ideas and objects	2.0	2.0	2.0	2.0	35	227.50	1.43	0.152
20	Extent of giving cues	2.0	2.0	2.0	2.0	33	204.00	1.37	0.172
21	Skill of giving cues	2.0	2.0	2.0	3.0	36	333.00	0.00	1.000
22	Skill of responding to cues	2.0	2.0	2.0	2.0	32	247.50	0.31	0.758
23	Intensity of showing positive affect	2.0	2.0	2.0	2.0	31	241.00	0.14	0.891
24	Intensity of interacting with objects	2.0	2.0	2.0	2.0	35	288.00	0.44	0.658
25	Skill of interacting with objects	2.0	2.0	2.0	2.0	37	323.00	0.43	0.658
26	Skill of transitioning between activities	2.0	2.0	2.0	2.0	25	156.00	0.17	0.861

*p was >0.05, there was a significant difference between the indoors score versus the outdoor score for children with HIV/Aids.

Table 3.4: Mann Whitney U test comparing TD vs HIV + for indoors ToP scores item analysis

		Mann-Whitney U Test for indoors ToP scores by diagnosis. Marked tests are significant at p <.05000			
	Variable	Rank Sum TD	Rank Sum HIV	U	P Value
1	Extent of being engaged	2722.50	1933.50	943.50	0.141
2	Intensity of being engaged	2649.50	2006.50	1016.50	0.350
3	Skill of being engaged	2696.00	1960.00	970.00	0.203
4	Extent of deciding what to do	2746.50	1909.50	919.50	0.099
5	Intensity of interacting with objects	2679.00	1977.00	987.00	0.251
6	Intensity of persistence	2835.50	1820.50	830.50	*0.021
7	Skill of modifying task requirements	2890.00	1766.00	776.00	*0.006
8	Extent of being involved in the process	2615.50	2040.50	1050.50	0.493
9	Extent of pretends	2835.50	1820.50	830.50	*0.021
10	Skill of pretending	2911.50	1744.50	754.50	*0.004
11	Extent of using people and objects unconventionally	2839.00	1817.00	827.00	*0.019
12	Skill of using people and objects unconventionally	2792.50	1863.50	873.50	*0.046
13	Skill of negotiating needs	2531.00	2029.00	1039.00	0.540
14	Extend of playing with others	2696.00	1960.00	970.00	0.203
15	Intensity of playing with others	2773.50	1882.50	892.50	0.064
16	Skill of playing with others	2716.00	1940.00	950.00	0.155
17	Skill of supporting the play of others	2758.00	1898.00	908.00	0.083
18	Skill of initiating new activities	2744.00	1912.00	922.00	0.104
19	Skill of sharing ideas and objects	2779.50	1876.50	886.50	0.058
20	Extent of giving cues	2644.00	2012.00	1022.00	0.373
21	Skill of giving cues	2816.00	1840.00	850.00	*0.030
22	Skill of responding to cues	2601.00	1959.00	969.00	0.256
23	Intensity of showing positive affect	2612.00	2044.00	1054.00	0.512
24	Intensity of interacting with objects	2623.00	2033.00	1043.00	0.462
25	Skill of interacting with objects	2734.00	1922.00	932.00	0.120
26	Skill of transitioning between activities	2702.50	1953.50	963.50	0.185

*p<0.005 there was a significant difference between the indoors score versus the outdoor score for children with HIV/Aids. Mann Whitney test was also used to compare the outdoors ToP item scores for typically developing children against children with HIV. Significant differences were noted on fourteen item scores (See Table 6 below).

3.5.5 *Differences in elements of playfulness based on ToP item scores between HIV+ and TD*

Based on Bundy's model of playfulness in children (Bundy, 1997), the ToP items were also grouped together according to the four elements of playfulness: intrinsic motivation, internal control, freedom to suspend reality, and framing. Children with HIV scored significantly lower than typically developing children on ability to suspend reality and framing for both indoor and outdoor environments for most items (see Table 3.5). For the elements of internal control and intrinsic motivation within the indoor environment, only modifying the task (U = 776.0; p = 0.006) and persist (U = 830.5; p = 0.021) were significantly lower for HIV positive compared with typically developing children. Conversely for the outdoor environment, significant differences were noted for seven of the 17 items for the elements of internal control and intrinsic motivation.

Table 3.5: Differences in elements of playfulness based on ToP item scores between TD and HIV+

Playfulness Element		**ToP item**	**Indoor**		**Outdoor**	
			U	***p*-value**	***U***	***p*-value**
Internal control	1	Extent of deciding what to do	919.50	0.099	780.00	*0.011
	2	Intensity of interacting with objects	987.00	0.251	1025.50	0.385
	3	Skill of modifying task requirements	776.00	**0.006	736.50	**0.002
	4	Skill of interacting with objects	1043.00	0.462	733.00	**0.002
	5	Skill of transitioning between activities	963.50	0.185	901.50	0.074
	6	Skill of negotiating needs	1039.00	0.540	806.50	*0.012
	7	Extent of playing with others	970.00	0.203	1040.00	0.448
	8	Intensity of playing with others	892.50	0.064	909.00	0.085
	9	Skill of playing with others	950.00	0.155	777.00	*0.010
	10	Skill of supporting the play of others	908.00	0.083	955.50	0.226
	11	Skill of initiating play	922.00	0.103	891.50	0.090
	12	Skill of sharing ideas and objects	886.50	0.058	852.00	*0.032
Suspension	of 13	Extent of pretending	830.50	*0.021	822.50	*0.018
Reality	14	Skill of pretending	754.50	**0.004	701.00	**0.002
	15	Extent of using people/objects unconventionally	827.00	*0.020	776.00	**0.006
	16	Skill of using people/ objects unconventionally	873.50	*0.046	757.00	**0.004
Intrinsic	17	Extent of being engaged	943.50	0.141	968.50	0.198
Motivation	18	Intensity of being engaged	1016.50	0.350	916.00	0.094
	19	Extent of being involved in the process	1050.50	0.493	1020.50	0.365
	20	Intensity of persistence	830.50	*0.021	786.50	**0.008
	17	Intensity of showing positive affect	1054.00	0.512	920.50	0.100
Framing	22	Extent of giving cues	1022.00	0.373	896.50	0.069
	23	Skill of giving cues	850.00	*0.031	689.00	**0.001
	24	Skill of responding to Cues	969.00	0.256	776.00	**0.006
	25	Skill of being engaged	795.00	0.203	795.00	*0.010

Note. *$p < 0.05$; ** $p < 0.01$ - there was a significant difference between typically developing children and children with HIV/Aids.

3.5.6 *ToP item scores for Social Skills:*

There was a significant difference between HIV positive and typically developing children on five of the nine ToP social skills items for the outdoor play (negotiate, shares, social play, giving cues, and responding to cues). HIV positive children scored significantly lower than typically developing children on giving cues (U = 850; p = 0.03) for indoor play. See table **Error! Reference source not found.** for more details.

Table 3.6: Differences on ToP Social Skill item scores between TD and HIV+

		INSIDE		**OUTDOOR**	
ToP item	**Brief Item Description**	**U**	**p Value**	**U**	**p Value**
Initiate	The child's skill/ability to initiate a new activity with another	922.00	0.103	891.50	0.090
Negotiate	The child's skill/ability to negotiate with others using 'give and take'	1039.00	0.540	806.50	*0.012
Shares	The child's skill/ability to allow others to use toys or ideas about the game	886.50	0.058	852.00	*0.032
Supports	The child's skill of helping others; using verbal support or by physical assistance	908.00	0.083	955.50	0.226
Social Extent	The extent/proportion of time the child interacts with others	970.00	0.203	1040.00	0.448
Social Intensity	The intensity/depth of the child's interactions with other's during play	892.50	0.064	909.00	0.085
Social Skill	The child's skill/ability to interact with others in cooperative and competitive play	950.00	0.155	777.00	*0.010
Giving Cues	The child's skill/ability to give verbal and non-verbal cues to others	850.00	*0.031	689.00	*0.001
Responds to Cues	The child's skill/ability to respond to others' verbal and non-verbal cues	1022.00	0.373	776.00	*0.069

*p<0.005 there was a significant difference between typically developing children and children with HIV/Aids

3.6 Discussion

This study compared the play profiles of children with HIV against age and gender matched typically developing children. Both children with HIV and typically developing children involved in this study were living in the same socioeconomic contexts. Generally, children with HIV involved in this study exhibited lower levels of playfulness as compared to typically developing children. This is the only study that we are aware of that explored the impact of HIV/Aids on the play profiles of children who are HIV positive by comparing their profiles against matched typically developing children. Most studies have investigated the impact of HIV on neuro-cognition (Mlambo et al., 2017) and neurodevelopment of children (Kandawasvika et al., 2011). Studies on play profiles of children have focused mainly on children with conditions such as ADHD (Wilkes-Gillan et al., 2014), Autism (Harkness & Bundy, 2001), foetal alcohol syndrome (Pearton et al., 2014) and none has focused on children with HIV.

3.6.1 *Indoor versus Outdoor play*

Play transactions take place between the child and his/her environment (Lynch et al., 2016). Results from this study showed that children with HIV were less playful outdoors as compared to typically developing children. Generally, more support is needed for outdoor play, as it is characterised by more physical and social interaction than indoor play. Similarly, a study by Pearton et al. (2014) observed children with foetal alcohol syndrome playing outdoors in the playgrounds and found that they had reduced playfulness levels as compared to typically developing children. Similarly, children with persistent asthma were reported to experience restricted outdoor play (Holderness et al., 2017). These findings are supported by a systematic review on outdoor play decisions by caregivers (Sterman et al., 2016) that reported that children with disabilities are less playful outdoors and highlighted that caregivers often make decisions about where and how children play.

Most of the caregivers of children with HIV (26; 59.0%) did report that they spent more time with their children as compared to caregivers of typically developing children. Similar findings were echoed from caregivers of children with congenital heart diseases who reported that they spent more time with their children (Sabzevari & Nematollahi, 2016) because more is required in the care of their children. Another study pointed out that caregivers wanted to be with their children most of the time, as a way of protecting them from stigma that is

commonly associated with being diagnosed with HIV/Aids (Munambah et al., 2020). Caregiver involvement in the play of their children has potential to hamper or promote play. Human, socio-cultural attitudes and poverty, have the potential to prevent or limit opportunities for children to engage and participate in play (Lynch et al., 2016). There are many things that compete with play (Ramugondo, 2012) or restrict children's ability to participate in it, thus leading to occupational deprivation. This does not only deprive this child opportunity to play and interact with others, but it may also affect him/her psychologically.

The findings provide evidence to support the need for interventions to improve play in children with HIV. In this study, the indoor environment constituted a room with standard toys and both children with and without HIV showed similar levels of play, as compared to the outdoor environment which was at the children's respective homes. Similarly to a study by Skaines et al. (2006), children with autism spectrum disorders also performed better in a structured environment. The role played by the environment which includes both the social environment, for example the influences of other players and caregivers, and the physical environment, which involves physical access and the availability of developmentally appropriate play materials cannot be underestimated in play (Rigby & Gaik, 2007). Focus on the environment is particularly important to occupational therapy because it is difficult to influence the play of a child without disrupting the play flow. However, Occupational Therapists can play a key role in enabling play occupations for children with HIV/Aids through manipulating the environment; thereby removing barriers that limit play while adapting the environment to promote play (Rebeiro, 2001).

3.6.2 *Elements of play*

Children with HIV performed similar to typically developing children with regards to the elements of intrinsic motivation and internal control. Intrinsic motivation occurs when some aspect of the activity itself provides the impetus for the child to play and internal control is the extent to which the child feels in charge of their actions (Skaines et al., 2006). A study using grounded theory of inquiry by De Santis et al. (2013) reported how people with HIV/Aids develop resilience through a process of motivation, management and mastery. Health professionals can leverage on this resilience to develop effective interventions for children with HIV.

Children who are HIV positive performed significantly poorer than typically developing children on the elements of suspending reality and framing for both indoor and outdoor environments. Experiencing difficulties in suspension of reality and framing could be explained by the complex skills involved in these elements which require higher cognitive abilities, thus making it more challenging for children with HIV who are at higher risk of having neuro-cognitive impairments (Mlambo et al., 2017). Suspension of reality is a very important aspect of play and is related to social aspects of play. For example, object substitution ability (suspending the reality of an object in play) is related to social interaction during play (Uren & Stagnitti, 2009). Framing requires an understanding of social rules and allows players to support their playmates during play (Pearton et al., 2014). Play skills are more refined when the child continues to engage in more play. Thus, more opportunities for children with HIV to engage in social play in safe and supportive environments could assist these children in developing play skills.

3.6.3 *Social play:*

Children with HIV performed poorly on five of the nine ToP social play items for outdoor play. Social play is exhibited when a child engages in play with a peer within a social context. However, children with HIV could have exhibited poor social play because they often have limited opportunities to play as some of their time is spent at the hospital/clinic for medical reviews or when they are actually not feeling well. Cordier et al. (2010b) also found that children with attention deficit hyperactivity disorders (ADHD) performed poorly in social play as compared to typically developing children. In their study, they also pointed out that social rejection by peers could have caused children with ADHD to want to play with their siblings or other children with social and behavioural difficulties. Stigma related to HIV and deficits in social play due to limited play opportunities can lead to children developing low self-esteem and become socially isolated. Conversely, frequent engagement in social play with peers has a ripple effect as it further supports peer engagement, social competence, cooperation, problem solving and communication (Wilkes-Gillan et al., 2014).

3.6.4 *Contextual Factors*

Despite being matched for age, an analysis of demographic data revealed that children with HIV were enrolled in lower grades as compared to their counterparts who are typically

developing. A study conducted in South Africa found that the most common disabilities reported in children with HIV were developmental delays, cognitive and behavioural difficulties and communication difficulty, all of which are likely to affect these children's functioning at school (Potterton et al., 2016). Hence, as a result of HIV, children may start school later and progress academically slower than their typically developing counterparts.

One interesting finding from this study was that children with HIV more frequently played with older children compared with typically developing children who were more likely to play with younger children. Children have a tendency to play with playmates who are skilled players so as to compensate for their own shortcomings (Cordier et al., 2010c). For example, in this study, children with HIV have been reported to have challenges with their social play when compared with typically developing children. It is therefore plausible that children with HIV/Aids were more likely to engage with older playmates who are able to scaffold their play, thereby extending the play frame. A study by (Cordier et al., 2010c) also revealed that children with ADHD had challenges in finding playmates and mostly relied on siblings for playmates.

Most children recruited were on first line of ART therapy and thus, were likely to be those children who were compliant with taking medication. This could have been as a result of recruitment being done at the hospital where children had come with their caregivers to collect medications. We therefore postulate that the impact of HIV/Aids on the play of children might be more severe if we had recruited participants in the community involving families with children who are HIV positive and who are less compliant with treatment adherence.

In this study, most caregivers of children who are HIV positive were informally employed. This may be due to the prevailing economic challenges in Zimbabwe which has resulted in most people being engaged in informal employment. Informal employment can be defined as, "…system of trade or economic exchange used outside state controlled or money based transactions and this includes among other transactions street trading" (Manjokoto & Ranga, 2017, p. 25). The current economic crisis in Zimbabwe which is characterised by reduced industrial productivity and high levels of unemployment (McIndoe-Calder et al., 2019), has affected the occupations that ordinary citizens engage in every day. In rural Zimbabwe, everyday doings of both children and adults are mainly centred on survival (Manjengwa et al., 2016). Economic factors that threaten survival, combined with cultural and relational practices, are likely to limit engagement and participations in meaningful occupations, such

as play, for children. Children like to play when they feel safe, and the environment is supportive of play. Deprivation of basic necessities of life is associated with increased risk to poor health outcomes in children and threatens their safety and creates stress which overall may affect their engagement in play (Leadley & Hocking, 2017).

3.7 Limitation

The HIV/Aids sample was recruited at a hospital. Hence there are chances that the children with HIV included in this study were the ones coming for medical reviews who are likely to have been compliant with medication. There are chances that a proportion of children who are not consistent in attending medical reviews could have been left out in this study. This study was a matched control comparative study, hence could not report on the causes or other underlying issues that either promote or hinder play in children with HIV. While outside the scope of this paper, there is a need to develop a comprehensive occupational profile for children with HIV/Aids.

3.8 Key points for Occupational Therapy

1. There is a need to develop interventions to improve the play of children with HIV/Aids.
2. Outdoor play may be a key focus of interventions for children with HIV/Aids.
3. Occupational therapists play a key role in restructuring the environment to promote play in children with HIV/Aids.

3.9 References

1. Bank, T. (2013). How we classify countries. *The World Bank http://data. worldbank. org/about/country-classifications. Accessed*, *13*, 10-13.
2. Bond, T. G., & Fox, C. M. (2007). Fundamental measurement in the human sciences. *Chicago, IL: Institute for Objective Measurement*.
3. Bronson, M. R., & Bundy, A. C. (2001). A correlational study of a test of playfulness and a test of environmental supportiveness for play. *The Occupational Therapy Journal of Research*, *21*(4), 241-259.
4. Bundy, A. (1997). Play and playfulness: What to look for. *Play in occupational therapy for children*, 52-66.
5. Bundy, A. C., Nelson, L., Metzger, M., & Bingaman, K. (2001). Validity and reliability of a test of playfulness. *The Occupational Therapy Journal of Research*, *21*(4), 276-292.
6. Campbell, C., Scott, K., Nhamo, M., Nyamukapa, C., Madanhire, C., Skovdal, M., Sherr, L., & Gregson, S. (2013). Social capital and HIV competent communities: the role of community groups in managing HIV/AIDS in rural Zimbabwe. *AIDS care*, *25*(sup1), S114-S122.
7. Cordier, R., Bundy, A., Hocking, C., & Einfeld, S. (2010, Apr). Comparison of the play of children with attention deficit hyperactivity disorder by subtypes. *Aust Occup Ther J*, *57*(2), 137-145. https://doi.org/10.1111/j.1440-1630.2009.00821.x
8. Cordier, R., Bundy, A., Hocking, C., & Einfeld, S. (2010a). Empathy in the play of children with attention deficit hyperactivity disorder. *OTJR: Occupation, Participation and Health*, *30*(3), 122-132.
9. Cordier, R., Bundy, A., Hocking, C., & Einfeld, S. (2010b). Playing with a child with ADHD: A focus on the playmates. *Scandinavian Journal of Occupational Therapy*, *17*(3), 191-199.
10. Dadson, P., Brown, T., & Stagnitti, K. (2020). Relationship between screen-time and hand function, play and sensory processing in children without disabilities aged 4–7 years: A exploratory study. *Australian Occupational Therapy Journal*.
11. De Santis, J. P., Florom-Smith, A., Vermeesch, A., Barroso, S., & DeLeon, D. A. (2013). Motivation, management, and mastery: a theory of resilience

in the context of HIV infection. *Journal of the American Psychiatric Nurses Association, 19*(1), 36-46.

12. Demmer, C. (2011, Jul). Experiences of families caring for an HIV-infected child in KwaZulu-Natal, South Africa: an exploratory study. *AIDS care, 23*(7), 873-879. https://doi.org/10.1080/09540121.2010.542123
13. Garin, O., Ayuso-Mateos, J. L., Almansa, J., Nieto, M., Chatterji, S., Vilagut, G., Alonso, J., Cieza, A., Svetskova, O., & Burger, H. (2010). Validation of the" World Health Organization Disability Assessment Schedule, WHODAS-2" in patients with chronic diseases. *Health and quality of life outcomes, 8*(1), 51.
14. Halfon, S. (2017). Play profile constructions: An empirical assessment of children's play in psychodynamic play therapy. *Journal of Infant, Child, and Adolescent Psychotherapy, 16*(3), 219-233.
15. Halfon, S., Cavdar, A., Orsucci, F., Schiepek, G. K., Andreassi, S., Giuliani, A., & de Felice, G. (2016). The Non-linear Trajectory of Change in Play Profiles of Three Children in Psychodynamic Play Therapy. *Front Psychol, 7*, 1494. https://doi.org/10.3389/fpsyg.2016.01494
16. Hamm, E. M. (2006). Playfulness and the environmental support of play in children with and without developmental disabilities. *OTJR: Occupation, Participation and Health, 26*(3), 88-96.
17. Harkness, L., & Bundy, A. C. (2001). The test of playfulness and children with physical disabilities. *The Occupational Therapy Journal of Research, 21*(2), 73-89.
18. Holderness, H., Chin, N., Ossip, D. J., Fagnano, M., Reznik, M., & Halterman, J. S. (2017). Physical activity, restrictions in activity, and body mass index among urban children with persistent asthma. *Annals of Allergy, Asthma & Immunology, 118*(4), 433-438.
19. Kandawasvika, G. Q., Kuona, P., Chandiwana, P., Masanganise, M., Gumbo, F. Z., Mapingure, M. P., Nathoo, K., & Stray-Pedersen, B. (2015). The burden and predictors of cognitive impairment among 6-to 8-year-old children infected and uninfected with HIV from Harare, Zimbabwe: a cross-sectional study. *Child Neuropsychology, 21*(1), 106-120. https://www.tandfonline.com/doi/pdf/10.1080/09297049.2013.876493?needAccess=true

20. Kandawasvika, G. Q., Ogundipe, E., Gumbo, F. Z., Kurewa, E. N., Mapingure, M. P., & Stray-Pedersen, B. (2011). Neurodevelopmental impairment among infants born to mothers infected with human immunodeficiency virus and uninfected mothers from three peri-urban primary care clinics in Harare, Zimbabwe. *Developmental Medicine & Child Neurology, 53*(11), 1046-1052.
21. Leadley, S., & Hocking, C. (2017). An occupational perspective of childhood poverty. *New Zealand Journal of Occupational Therapy, 64*(1), 23.
22. Lynch, H., Hayes, N., & Ryan, S. (2016). Exploring socio-cultural influences on infant play occupations in Irish home environments. *Journal of occupational science, 23*(3), 352-369.
23. Lynch, H., & Moore, A. (2016). Play as an occupation in occupational therapy. British Journal of Occupational Therapy, 79(9), 519– 520. https://doi.org/10.1177/0308022616664540
24. Manjengwa, J., Matema, C., & Tirivanhu, D. (2016). Understanding urban poverty in two high-density suburbs of Harare, Zimbabwe. *Development Southern Africa, 33*(1), 23-38.
25. Manjokoto, C., & Ranga, D. (2017). Opportunities and challenges faced by women involved in informal cross-border trade in the city of Mutare during a prolonged economic crisis in Zimbabwe. *Journal of the Indian Ocean Region, 13*(1), 25-39.
26. Masanjala, W. (2007). The poverty-HIV/AIDS nexus in Africa: a livelihood approach. *Social science & medicine, 64*(5), 1032-1041.
27. McIndoe-Calder, T., Bedi, T., & Mercado, R. (2019). Hyperinflation in Zimbabwe. In *Hyperinflation in Zimbabwe* (pp. 9-25). Springer.
28. Milteer, R. M., Ginsburg, K. R., Council On, C., Media, Committee On Psychosocial Aspects Of, C., & Family, H. (2012, Jan). The importance of play in promoting healthy child development and maintaining strong parent-child bond: focus on children in poverty. *Pediatrics, 129*(1), e204-213. https://doi.org/10.1542/peds.2011-2953
29. Mlambo, T., Jelsma, J., Rusakaniko, S., Dale, N., & Chingono, A. (2017). Predictors of Zimbabwean children's neuro-cognitive performance on the Detroit Tests of Learning Aptitude fourth edition (DTLA-4): Implications

for policy, practice and research. *World Federation of Occupational Therapists Bulletin, 73*(2), 94-106.

30. Munambah, N., Gretschell, P., & Sonday, A. (2020). Being a mother of a child with HIV-related Neurodevelopmental Disorders in the Zimbabwean Context. *South African Journal of Occupational Therapy, 50*(1), 35-40.
31. Pearton, J. L., Ramugondo, E., Cloete, L., & Cordier, R. (2014). Playfulness and prenatal alcohol exposure: A comparative study. *Australian Occupational Therapy Journal, 61*(4), 259-267.
32. Potterton, J., Hilburn, N., & Strehlau, R. (2016, May). Developmental status of preschool children receiving cART: a descriptive cohort study. *Child Care Health Dev, 42*(3), 410-414. https://doi.org/10.1111/cch.12321
33. Ramugondo, E. L. (2012). Intergenerational play within family: The case for occupational consciousness. *Journal of occupational science, 19*(4), 326-340.
34. Rebeiro, K. L. (2001). Enabling occupation: The importance of an affirming environment. *Canadian Journal of Occupational Therapy, 68*(2), 80-89.
35. Rigby, P., & Gaik, S. (2007). Stability of playfulness across environmental settings: a pilot study. *Phys Occup Ther Pediatr, 27*(1), 27-43. https://www.ncbi.nlm.nih.gov/pubmed/17298939
36. Sabzevari, S., & Nematollahi, M. (2016). The burden of care: mothers' experiences of children with congenital heart disease. *International journal of community based nursing and midwifery, 4*(4), 374.
37. Skaines, N., Rodger, S., & Bundy, A. (2006). Playfulness in children with autistic disorder and their typically developing peers. *British Journal of Occupational Therapy, 69*(11), 505-512.
38. Skard, G., & Bundy, A. C. (2008). Test of playfulness. In *Play in occupational therapy for children* (pp. 71-93). Elsevier.
39. Skeen, S., Sherr, L., Tomlinson, M., Croome, N., Ghandi, N., Roberts, J. K., & Macedo, A. (2017). Interventions to improve psychosocial well-being for children affected by HIV and AIDS: a systematic review. *Vulnerable Child Youth Stud, 12*(2), 91-116. https://doi.org/10.1080/17450128.2016.1276656

40. Sterman, J., Naughton, G., Froude, E., Villeneuve, M., Beetham, K., Wyver, S., & Bundy, A. (2016). Outdoor play decisions by caregivers of children with disabilities: A systematic review of qualitative studies. *Journal of Developmental and Physical Disabilities, 28*(6), 931-957.
41. Uren, N., & Stagnitti, K. (2009). Pretend play, social competence and involvement in children aged 5–7 years: The concurrent validity of the Child-Initiated Pretend Play Assessment. *Australian Occupational Therapy Journal, 56*(1), 33-40.
42. Wilkes-Gillan, S., Bundy, A., Cordier, R., & Lincoln, M. (2014). Eighteen-month follow-up of a play-based intervention to improve the social play skills of children with attention deficit hyperactivity disorder. *Australian Occupational Therapy Journal, 61*(5), 299-307.

4 CHAPTER 4: Caregiver's perspectives on play of children with HIV/AIDS

4.1 Introduction

Perspectives of caregivers on the play of children with HIV/Aids living in a low resourced setting are presented in this chapter. In this study, caregivers are viewed as key stakeholders of the play-based intervention framework as they are the main custodians of children with HIV/Aids. Caregivers provided important insights on how the context shaped the play of children with HIV/Aids living in a low resourced setting. The study design and the data collection procedures will be shared. Findings from this study will be presented as themes. Discussion of the findings as well as implications for the study is shared in conclusion to this chapter.

This chapter is a journal manuscript submitted to the British Journal of Occupational Therapy. The manuscript is currently under review. The article is presented as Microsoft Word document and has been formatted according to the British Journal of Occupational Therapy guidelines. A list of references for this chapter is presented at the end of the chapter.

Abstract

Background: Although play is viewed as a childhood occupation that is spontaneous, it can be limited in children with HIV/Aids. This study explored the perspectives of caregivers from Zimbabwe on the play of children with HIV/Aids.

Methodology: A descriptive qualitative research approach was used to explore the perceptions of caregivers on play of children living with HIV/Aids. Fifteen caregivers of children aged 4-9 years diagnosed with HIV/Aids were purposively sampled. Two interviews were carried out with each of the caregivers. Findings were analysed thematically.

Findings: Four major themes were generated from the study: '*Ubuntu* is no more'; 'Survival is primary (*chikuru kurarama*)'; 'Play affirms that my child is still like other children'; 'More is required for this child'. Although issues of survival were paramount, caregivers were able to highlight the importance of play in affirming childhood, identifying the specific needs for play for children with HIV/Aids.

Conclusion and Significance: Play, like all other human occupation, is contextually situated. Poverty and health status are key in shaping how families prioritise play. However, the ability to play for a child with HIV/Aids also seems to mitigate stigma and may disrupt the 'HIV *is* death' narrative.

Key Words: Occupational Therapy, children, Play, HIV/Aids, context.

4.2 Background Information

This paper presents findings from an ongoing project aimed at developing a play-based intervention for children living with HIV/Aids living in low resourced setting. The findings emerged out of the qualitative aspect of the broader study, seeking to understand the play of children with HIV/Aids living in low resourced setting from the perspective of their caregivers. The introductory section of the paper provides an occupational perspective to the concept of play in childhood, situating this concept within occupational therapy practice and research involving children with HIV/Aids. The subsequent section describes the methodology used in the study, followed by the presentation of findings. The paper concludes with a discussion section on the contextually situated nature of play. This section highlights some of the contextual issues occupational therapists need to consider when designing and implementing play-based interventions for children living with HIV/Aids in low resourced settings.

4.3 Play in occupational therapy for children

Play is a common childhood occupation (Cordier et al., 2009) and is frequently used in occupational therapy as a medium for intervention with children. Play is fun and using it as a medium for interventions is likely to make them more enjoyable (Lynch et al., 2018). Children have the ability to turn any activity into play and occupational therapists have leveraged on this to use play as a means to cultivate general skills needed to perform functional activities (Lynch & Moore, 2016). Play has thus been used in occupational therapy for children, especially those with chronic health conditions and disabilities (Dender & Stagnitti, 2015).

Play is defined as ‘a transaction with the environment that is intrinsically motivated, internally controlled and free from the constraints of reality’ (Skard & Bundy, 2008, p. 71). Although children have a propensity to play, at times they fail to engage and participate due to factors such as illness and environmental deprivation, which often limit opportunities. Restricted opportunities to engage in play are likely to affect the child’s development, with long-term effects likely noticed only in adulthood. The conceptualisation of play in occupational therapy thus ceases to be narrowed down to the child, but also considers the environment and the possibilities of enabling play occupations in context (Cordier et al., 2009). The need to promote play is integral to holistic occupation-based occupational therapy

practice involving children.

4.4 Play, HIV/Aids and the impact of contextual factors

Children with HIV/Aids are at a higher risk of having developmental delays (Hutchings & Potterton, 2014). These children were also observed to have neuro–cognitive impairments (Mlambo et al., 2017), which are likely to affect engagement and participation in play. Although the studies mentioned here point to potential limitations in the play of children with HIV/Aids, no research has sought to understand the play of children with HIV/Aids living in low resourced settings, especially from caregivers' perspectives. A recent systematic review conducted by Munambah, Cordier, Speyer, et al. (2020) revealed that there are no studies that have sought to understand play of children with HIV/Aids through comparing their play profiles against typically developing children. This is of concern especially in Sub-Saharan Africa where approximately 90% of the 1.8 million children infected with HIV/Aids globally, reside (Joint United Nations Programme on, 2015).

Apart from illness, there are many factors that compete with play (Ramugondo, 2012) or restrict children's ability to participate in it. Play is often challenged by contextual factors such as stigma, neighbourhood violence and limited resources available for children living in poverty (Milteer & Ginsburg, 2012). Rapid social change in certain parts of the world has resulted in play as understood by families and whole communities and across generations, being eroded (Ramugondo, 2012). Furthermore, increased use of electronic media, pressured lifestyles of adults and the growing emphasis on academic preparation are some of the factors that are contributing to the diminished opportunities for play (Lynch et al., 2018).

The terms environment and context have been used to mean more or less the same thing in occupational therapy (Rodger & Kennedy-Behr, 2019). In this paper, these terms will be used interchangeably. Occupational therapy has extended its individualistic approach in understanding occupation by acknowledging how the broader context influences engagement and participation in occupations (Kuo, 2011). Occupation provides a medium through which humans transact with their contexts (Cutchin & Dickie, 2013). Context includes the physical, social, cultural and political aspects (Cutchin et al., 2008; Hocking, 2020) that affect the day to day functioning of individuals and collectives (Fogelberg & Frauwirth, 2010; Ramugondo, 2015).

Occupational therapists have unique expertise to understand persons and their occupations in

context, as well as how to enable occupational performance and participation (Rodger et al., 2010). However, Hammell and Iwama (2012) pointed out that most models and theories that inform practice have been developed in the West. This could be problematic when such models are applied blindly to African contexts (Ramugondo, 2018). Lately, occupational therapists are increasingly becoming aware of the significance of culture and ways in which cultural behaviours and beliefs shape everyday doing (Lynch et al., 2018). There is therefore a growing need to develop context-based conceptual models that promote play in children. For effective interventions to be developed there is a need to understand context and how engagement and participation in play by children with HIV/Aids is shaped, especially in low resourced settings. This study aims to explore and describe the play of children with HIV/Aids from caregivers' perspectives. The research question that was asked was, what are the perspectives of caregivers on the play of children with HIV/Aids living in low resourced settings?

4.5 Methodology

A qualitative descriptive study design was used to gain an understanding of the play of children with HIV/Aids in low resourced settings from caregivers' perspectives. This study design was selected because it allows for open-ended questions and exploration of perceptions and experiences. Qualitative descriptive study design draws from naturalistic inquiry (Sandelowski, 2000), which entails presentation of the facts regarding the phenomenon under inquiry in everyday language. Qualitative descriptive study design was selected as there was need to gain information from those experiencing the phenomenon under study within the confines of limited time and resources (Bradshaw et al., 2017).

Study Participants: Fifteen caregivers of children diagnosed with HIV, whose children had been observed playing in the earlier phase of the study were purposively selected using maximum variation to participate in this study. Maximum variation involves selection of participants who cover the spectrum of positions and perspectives in relation to the phenomenon that one is studying (Patton, 1990). In this study, maximum variation was used to select caregivers of different ages, level of education, marital status. Also, caregivers had different parental roles, varying numbers of children under their care, and their children were of different ages. For the purposes of this study, a caregiver is defined as an adult (above legal age of 18 years), primarily responsible for the care of the child and is able to give consent on behalf of the child. See table 4.1 below for the demographics of the caregivers.

Ethical Approvals: Ethical approval for the study was obtained from the University of Cape Town (HREC REF: 640/2017). In Zimbabwe where data were collected, ethical approvals were obtained from the Medical Research Council of Zimbabwe (MRCZ REF: A/2364) and Joint Research and Ethics Committee (JREC REF: 163/18). Written informed consent was obtained from all the participants prior to participation in the study. Privacy and confidentiality of the caregivers was maintained throughout the research process.

Data collection tool: Data collection was done using in-depth interviews with the caregivers. An interview guide developed from the study objectives and adjusted based on the findings from earlier phases of the study was used to guide the researcher. Caregivers were asked on how their children played, barriers and facilitators to play, as well as what should be done to promote play of children living with HIV/Aids. Before data collection, the interview guide was reviewed by three experts in occupational therapy and qualitative research. Thereafter the guide was piloted with two of the caregivers and their data were included in this study.

Data Collection Procedure: Two interviews were carried out with each of the caregivers. An appointment for the interviews was set with each of the caregivers at a convenient date, time and place. Also, caregivers were free to choose the language they wanted the interviews to be conducted in and all chose to be interviewed in their native language (Shona). The estimated length of each interview was 45 minutes. Immediately after each interview, data was transcribed, translated to English and analysed before the next interview.

Data Analysis: Data were analysed thematically using a simplified version of the Stevick-Colaizz-Keen method detailed in Creswell (2007) and Moustakas (1994). During data analysis, the researcher revisited the original transcripts in Shona to retain the original meaning of the data. Shona terms were used in the manuscript if their deeper meanings were lost when translated into English. An iterative and reflexive process was done throughout analysis with data continuously reviewed back and forth to confirm or discredit original findings (Sandelowski, 2000). A technique of member checking was also used to ascertain that the findings were a true reflection of what the caregivers said (Krefting, 1991).

4.6 Findings

The study was aimed at understanding the play of children with HIV/Aids living in a low resourced setting, from the perspectives of the caregivers (Table 4.1). Four themes emerged from the data. Table 4.2 below presents the themes and categories.

Table 4.1: Participants of the study

Code	Age	Sex	HIV status of the caregiver	Age of child with HIV	Level of education	Relationship to Child with HIV	Time spent with HIV Positive Child (hrs/week)	Income ($)	Employment Status	Number of children cared for by caregiver
1	43	Female	Positive	9	Grade 1-7	Mother	8-20	101-200	Stay at home mum	2
2	44	Male	Positive	8	Form 3-4	Father	>20	201-300	Full time (formal) employment	3
3	41	Female	Positive	7	Form 3-4	Mother	>20	400-500	Small business operator	5
4	41	Female	Negative	6	Form 3-4	Foster Parent	8-20	Donations	Paid Volunteer	4
5	40	Female	Positive	5	Form 3-4	Mother	>20	1-100	Self employed	9
6	38	Female	Positive	9	Form 3-4	Mother	>20	1-100	Unemployed	3
7	39	Female	Positive	6	Grade 1-7	Mother	8-20	101-200	Vendor	0
8	47	Female	Positive	6	Form 3-4	Mother	<7	1-100	Vendor	2
9	31	Female	Positive	5	Form 1-2	Mother	>20	101-200	Not employed	0
10	33	Male	Positive	7	Form 3-4	Father	>20	1-100	Not employed	3
11	51	Female	Negative	8	Grade 1-7	Grand Mother	8-20	101-200	Vendor	1
12	47	Female	Positive	7	Form 3-4	Mother	8-20	1-100	Part time	3
13	43	Female	Positive	6	Form 3-4	Mother	8-20	101-200	Part time	2
14	55	Female	Negative	7	Form 1-2	Grandmother	8-20	101-200	Not employed	1
15	27	Female	Positive	5	Form 3-4	Mother	>20	101-200	Part time	2

Table 4.2: Themes and categories

Themes	Categories
Ubuntu is no more	1. No safe spaces to play 2. Child needs to be protected from stigma 3. No indigenous alternatives to promote play
Survival is primary (*chikuru kurarama)*	1. Incapacitated by poverty 2. Medication means life 3. Food a priority over play
Play affirms that my child is still like other children	1. Play disrupts the 'HIV *is* death' narrative 2. Play is more fun with others
More is required for a child with HIV	1. My child is different 2. More toys, more fun 3. As a caregiver, I need to do more to promote play

4.6.1 Ubuntu *is no more*

This theme draws from the caregivers' own childhood, juxtaposed against the current play experiences of their children, pointing to some of the contextual barriers to play. "*Ubuntu* is no more" reflects some of the changes in social and physical environments and how these have impacted on the play of children with HIV/Aids in this setting. *Ubuntu* refers to a shared ethical responsibility for humanity; how this is an ongoing process allowing for co-existence involving the individual and other people in a community (Ramugondo, 2015). Caregivers highlighted how in the past, through *Ubuntu,* elders would look after anyone's child without expecting any payment. For example, when children were playing in communal areas, elders (who are not caregivers of the children playing) would protect children from any potential danger. This has changed, with some elders now viewed as a threat instead.

> *"It's not safe to just let your child out, ...umm (swaying head sideways) people nowadays no longer have love for one another as in the old days." (Caregiver 1)*

Ubuntu was significant for outdoor play, as most children prefer to play outdoors, often involving running around and playing with mud. Forced by circumstances, caregivers at times keep their children indoors, often against the child's will. Indoor play is often restricted due to limited space.

> *"We live in a single room which is just divided by a curtain to separate the bedroom, no space for kids to play." (Caregiver 2)*

The current study was carried out in Harare (capital city of Zimbabwe) and in the peri-urban locations. Most of the caregivers involved in this study were staying on rented property and had limited space for children to play indoors or outdoors in the yard. Often the landlords were not supportive of children playing on their premises. On asking about designated play areas, caregivers raised concerns about safety and lack of security in these play-spaces. In most communities where the study took place; there were no clearly designated play areas for children except for the playgrounds at school. Children would often go and play at open spaces whose purpose is not known. Caregivers reported that these open spaces were not safe for children.

> *"People are now cruel. Children are now being targeted by criminals. Even us the adults! It used to be very safe back then, there is no longer anything called safe place these days." (Caregiver 6)*

Ubuntu as a communal ethic for a shared humanity means one must view another's child as their own. In a context where Ubuntu has been eroded, and where there is stigma against people with HIV/Aids, children with HIV/Aids are particularly vulnerable. Caregivers reported that their children needed to be protected against stigma. One of the caregivers shared her experience of how her child was stigmatised at school as a result of her HIV status. This means that children with HIV/Aids in this context also often barriers to schooling. Most of the caregivers had resorted to not disclosing their children's status for fear of the child being stigmatised.

> *"The problem in our communities is stigmatization (paused); it is a matter of concern to us, so you will try by all means to be very secretive." (Caregiver 5)*

Although some caregivers attested to not having personal experiences of being stigmatised, they remained afraid of stigma. Much of the fear stemmed from the fact that if the child's status is disclosed, this would imply an HIV positive status for the mother. Some thought that once other people knew the status of the child, other children may refuse to play with him or her.

Apart from the fear that other children will isolate the child during play, caregivers were also afraid of how adults would also treat the child. Caregivers, whose children know their own HIV status, have also told their children not to disclose their status to other children or people in the community. As a way of protecting the child from stigma and other adversities,

caregivers tend to also control the play of the children. Some caregivers reported that they dictate the times at which the child should play, whom they play with and where they play. In controlling the children, caregivers often beat, blame, or shout at the children.

> *"We just make sure she is playing close by us … if she is going beyond our approval, I normally give her a talking eye… and she will simply correct herself from the bad group or from the unwanted play." (Caregiver 2)*

Family migration in some instances could have also played a role in bringing about the sense that 'Ubuntu is no more', as most families no longer live together. Often grandparents, aunts and uncles are not available to play with the children. A number of caregivers reported that they decided to stay away from extended family members and would not allow their children to visit relatives due to fear that their HIV status may be exposed.

In the Shona culture, there is an expectation that the father should be shown respect in particular ways. A child has a specific way of talking to the father that shows respect, in ways that are restrictive. More freedom is accorded to children as they interact with grandparents, aunts and uncles. One caregiver narrated how culture restricted him, as a father, from playing with his daughter.

> *"Ummm…but as a father we play to a certain level. Yes! …but you should also leave room for respect, you should not play like an uncle and niece but I should play with her to a level that I would be able to be granted my respect as a father. …. because a child should feel free to say anything that she likes to her grandfather, …unfortunately the grandparents are in the rural areas, far away from us." (Caregiver 2)*

This has also led to indigenous play forms being less frequently practiced. Some caregivers held a belief that adults should not play with children, instead children should play with their own peers.

4.6.2 *Survival is primary (*chikuru kurarama*)*

The theme 'Survival is primary' emerges from the lived experience accounts of caregivers of children HIV/Aids in this study. Until recently, HIV/Aids was experienced as a fatal condition in Zimbabwe, and much of Sub-Saharan Africa. With the advent of antiretroviral

medication, this terminal illness changed to become a chronic condition. In the context of poverty, which is unfortunate reality in this study setting, the primary focus of caregivers is on things presumed to be linked to survival. Survival however in the context of HIV/Aids is not only about food per se, but that also the ability to remain compliant with taking medication. Anti-retroviral drugs on an empty stomach are a significant risk for children with HIV/Aids. Caregivers were thus mostly preoccupied with meeting basic needs for survival to the extent that not much focus was given to play. The phrase '*chikuru kurarama',* literally meaning 'better to be alive', was echoed by many caregivers who said that children's play was secondary as they focus on survival from one day to the other.

Caregivers reported that medication, which is mostly antiretroviral therapy, is of paramount importance when taking care of a child with HIV. Thus, caregivers prioritised giving medication above all responsibilities, because the survival of a child with HIV was viewed as tied to correctly complying with medication intake.

> *"Medication should be given on time and (one has to) manage that time, if you say you will give your child his or her medication at 8 let it be 8 and maintain that time." (Caregiver 11)*

The health team was also influential in making sure that parents adhere to the appropriate administration of medications. Counselling at the hospital is centred on complying with medication and proper nutritional intake. This notion was further accentuated by many parents having experienced their child's health deteriorating when they failed to give medication appropriately.

> *"I have seen with other parents (that) they do not give their children proper medication, the end result is you will face many challenges as that will affect the growth of your child." (Caregiver 10)*

Some of the effects of not taking medication included stunted growth, with some children presenting with opportunistic infections. Caregivers agreed that if medications are taken appropriately, then children's overall health and development improved, which is a prerequisite for children to engage in play.

"As parents, we should just encourage and support them (our children) in taking their medication so that a difference will not be noticed when he/she is playing with others unless they have been told so." (Caregiver 5)

In the struggle to survive, caregivers prioritised food provision for the children. Caregivers highlighted some challenges they face in providing food and taking care of children with HIV.

"The biggest challenge is the food issue; it is very hard for us to get food to an extent that we had to have delayed breakfast so as to coincide with lunch. We now only have tea here (at the clinic)." (Caregiver 15)

Although food is a basic need for all people, caregivers reported that it is different for children who are on antiretroviral medication as they require more food compared to other typically developing children. The struggle to provide food is complicated because children with HIV/Aids do not require just any food but they need to be given healthy food. Also, the food had to be well prepared and given at appropriate times. Caregivers narrated how at times it was difficult to find the right food that aids in boosting their children's immune system.

Caregivers reported that, once the children are fed, they looked happy and played for longer hours either by themselves or with other children. Pursuant to the above, some caregivers said that play should be accompanied by food.

"I think the playing aspect should be accompanied by food if possible as it helps a lot even to suppress stress on the child." (Caregiver 14)

Caregivers involved in this study came from low resourced settings and most did not have financial resources to meet basic needs for survival. Poverty was primarily due to lack of employment or other alternative means of income. The situation was exacerbated by the prevailing economic hardships in Zimbabwe, where most industries are functioning below capacity. The most common source of income in Zimbabwe is informal trade, especially of goods sourced in neighbouring countries. Other people are involved in small projects like gardening, chicken rearing and doing some short-term jobs (though erratic) for survival. Due to poverty, some caregivers either failed to enrol their children into school, or to pay fees for their children. Yet the school environment offers space and opportunities for children to play with their peers.

4.6.3 *Play affirms that my child is still like other children*

Caregivers narrated some of their joys experienced when they observed their children play against all odds. Play in many ways disrupted the 'HIV is death' narrative. One grandmother narrated how her daughter passed away and she had to take care of a sickly baby (her granddaughter) when everyone else refused to take custody of the baby.

> *"The child was very small and very pale, to be honest there was no sign of life… (Paused) There was nothing I could do because I am her only grandmother. I took the child with grief in my heart… umm … it was difficult. But thank God she has fully recovered." (Caregiver 14)*

The ability of a child to engage in play brought relief to the caregivers. Even when they are not feeling well, they try to engage in play.

> *"Even when he is not well, he gives himself time to play. Ah!! Sleeping! You would be shocked, because he will be gone!! The moment he sees his friends, he goes out to play." (Caregiver 13)*

Caregivers used play as a yardstick for constantly comparing the play of their children to typically developing children and were delighted when they saw little or no differences. Apart from seeking to nullify differences in play between children with HIV and those without HIV, caregivers also stated some of the physical, emotional and cognitive benefits of play. Caregivers also reported that their children learn new things through play and also learnt soft skills which caregivers thought was important in their development.

All caregivers involved agreed that play was more fun with others. Although caregivers were secretive about the status of their children, they were of the view that children with HIV should play with other typically developing children. Engaging in play with typically developing children was seen as a way of reducing stigma targeted at children with HIV/Aids.

> *"These children should not be separated, they should mix with other kids who are negative to reduce stigmatization and stress from the HIV affected children." (Caregiver 6)*

Some caregivers reported that they also engage in play with their children or have seen other adults playing with their children. However, caregiver involvement in play was generally centred on creating an environment that promotes play and providing things for the children to play with. For example, some caregivers described taking their children out to a family fun show as play. Some caregivers felt that provision of toys, creating time to play and allowing children to go out to play as some of the ways of getting involved in children's play.

4.6.4 *More is required for this child*

All the caregivers involved in this study reported that more is required in the care of their children. They also indicated that such care was foundational to enabling play. Compared with typically developing children, caregivers narrated some of the things they see children with HIV/Aids incapacitated to do and gave solutions to some of the problems they faced. Caregivers reported that some of their children with HIV/Aids had physical, behavioural and emotional problems. Some of the children were reported to be generally weak and some would fatigue easily during play.

> *"I have realized that he is not physically fit. One can notice it when they are playing. If he is slightly pushed he falls or when they are playing soccer, if he misses a kick he falls down." (Caregiver 7)*

Behavioural and emotional challenges highlighted by caregivers included being short tempered, signs of depression and problems in social skills. Caregivers also noted that children living with HIV had various challenges in both verbal and non-verbal communication. Some of the deficits in communication were visible during play.

> *"She is very short tempered…. I always think that her temper is caused by her condition. She ends up playing alone." (Caregiver 2)*

Most of the children involved in this study had not been screened for other impairments such as hearing, eye problems and behavioural problems. Caregivers were not aware of services they could access for their children apart from HIV medication. One caregiver was quick to blame herself saying that maybe she had spoiled the child. The lack of knowledge on some of these behavioural problems and possible interventions pose some challenges in parenting. Some caregivers reported how they would discipline the child without seeing much change from it.

"My child is very stubborn to an extent that even if you discipline him, he doesn't change and I have since given up." (Caregiver 9)

Caregivers felt that they could do more to promote play for their children. One of the things they mentioned was that children with HIV should be given more time to play. Play was viewed as a medium to get close to the child and promote bonding with the child. In that respect, caregivers felt they needed to be more involved in their children's play and expressed a desire for coaching in this regard, to be equipped with knowledge on how to promote play. Many of the caregivers highlighted that they had not had any session to discuss benefits of play and how they could promote play for their children, reporting that most of the counselling sessions they had at the hospital were centred on compliance with medication. Caregivers' interest in knowing more about play could have grown out from experiencing their children being observed playing at the clinic and at their home, as participants in a previous phase of the broader study.

"You should teach us how to play with them, in the same way we receive counselling at hospital. Tell us about these things. We need our children to do better." (Caregiver 13)

Sentiment among caregivers was that if more toys could be provided, their children could play more. Most children were reported not to have toys. Caregivers however, mentioned how most of the children make their own toys from a variety of things. This creativity in making toys could have been necessitated by the fact that most of them do not have specifically designed toys, as families could not afford to buy toys from shops. Some caregivers also attested to making low cost toys from locally available materials. Some of the materials included seeds from a variety of grains, empty jars and old clothes.

"One can improvise by using peanut butter containers. You can take material from clothes that you want to dispose of and sew nice dolls for your child." (Caregiver 11)

4.7 Discussion

This study is one of the few studies that have explored the play of children with HIV/Aids from the perspectives of caregivers. Findings revealed that the context in which play occurred for these children shaped their engagements. The condition of being HIV positive coupled with poverty and cultural beliefs, influenced how caregivers prioritised play. However,

despite contextual barriers, play opened possibilities for children with HIV/Aids. A significant finding of the study is that play seemed to mitigate stigma, disrupting the "HIV is death narrative". The findings also provide important insights on the play of children with HIV/Aids living in low resourced contexts, identifying factors that either limit or promote engagement and participation in play occupations.

Similar to Potterton et al. (2009), the current study found that children with HIV/Aids experienced physical, behavioural, emotional and communication deficits which impacted on their engagement and participation in play. Thus, there is need for early assessment and intervention for children with HIV/Aids to address these deficits. Of note in the current study, was that caregivers could identify some of these deficits but were not aware of the impact of these deficits on the development and wellbeing of their children and the services that they could benefit from. Positive strides of reducing mortality gained through the provision of antiretroviral therapy (Hutchings & Potterton, 2014) need to be complimented by improving the quality of life for these children. Occupational therapy plays a significant role in the early assessment and intervention for children with HIV/Aids.

Occupational therapists use a holistic approach which views the constructs; person, occupation and context as inextricably intertwined (Dickie et al., 2006). Thus, apart from deficits in the child as a result of HIV/Aids, a critical look at the context and how it promotes or hinders play in children is of significant importance. In the current study, caregivers reported that there were often no safe places for children to play. Play was often restricted to either indoors or somewhere close to the caregivers. Similarly, a study in an impoverished setting with typically developing children by Kimbro and Schachter (2011) also reported concerns of safety as one of the major reasons for limited outdoor play. Outdoor play offers various benefits on development and wellbeing. Children play when the environment is safe and supportive of play (Cordier et al., 2009), thus unsupportive environments can deprive children of play opportunities.

Poverty shaped the everyday occupations of caregivers and children involved in this study such that their everyday doing was centred on securing basic necessities for survival. Thus, children's play was often not a priority. Poverty in Zimbabwe has been worsened in recent years by the crippling macro socio-economic situation which has resulted in high unemployment rates, forcing most people to survive on informal jobs (Manjengwa et al., 2016). As a result of poverty, caregivers often face challenges in providing a healthy diet to

their children with HIV/Aids. The worst scenario of being deprived of basic necessities to life is that it may lead to illness and mortality (Leadley & Hocking, 2017). Lack of a healthy diet has implications on the general growth of children, affecting play and overall child health.

Apart from poverty, the depreciation of humanity expressed in the current study as *Ubuntu* is no more, also played a role in limiting the play of children with HIV/Aids. Caregivers in this study also feared HIV-related stigma from both adults and children; and as a way of protecting their children from stigma, they often controlled their play. This control of children's play by the caregivers can best be explained through a transactional view of human occupation, which draws on Dewey's action theory and highlights societal constrains on human aspirations, reflected in what they do every day (Cutchin et al., 2008, p. 159). As a result of stigma and consequent limited opportunities for play, caregivers inadvertently contributed to their children's occupational deprivation. Occupational deprivation has been defined as "social exclusion by restricting a population in diverse contexts from participating in occupations that would promote their health and well-being" (Whiteford, 2000, p. 201).

Play is shaped and influenced by parental beliefs and values (Lynch & Moore, 2016), as such an understanding of children's play from the perspectives of caregivers is important. Some caregivers involved in the current study believed that adults should not actively participate in play but should limit their role to providing resources for play; adult-child play was viewed as the reserve of grandparents, aunts and uncles. The configuration of family beyond parents/caregivers but involving 'extended' family members is often missed in most research studies done with a western conceptualisation of family. As theorisation in occupational therapy moves beyond a narrow western perspective of occupation (Ramugondo & Kronenberg, 2015), there is a need to continuously consider contextual factors which inform parental beliefs and value systems that impact on play as an occupation.

Children, like any another human being have an innate need for relations with others (Ramugondo & Kronenberg, 2015). Caregivers in this study reported that their children were happy when playing with their peers. As children engage in play with their peers, they imitate social actions and learn to interact with others (Cordier et al., 2009). Of interest in this study was that caregivers also reported how opportunities of play for children with HIV/Aids involving typically developing children can serve to fight stigma. Adopting the view of play as a collective occupation (Ramugondo & Kronenberg, 2015) offers a lens to view all the multiple actors involved and how they shape play occupations.

Findings from the current study support the notion that occupation is linked to health and wellbeing (Wilcock, 2007). Caregivers highlighted how through play, their children's health had improved. Engagement in play is one of childhood occupations that allow children to learn and develop fundamental motor, cognitive and socio-emotional skills (Lynch & Moore, 2016). In the current study, caregivers showed willingness to do more to promote play for their children, demonstrated some resourcefulness' in this regard, and a desire to be coached on how best to promote play.

4.8 Limitations of the study

The caregivers who participated in this study were recruited from caregivers of children with HIV/Aids whose children had participated in the earlier phase of the broader study which involved observing the child playing with a playmate at the clinic and home (chapter 3). All participants were recruited from outpatient clinics at two central hospitals. Therefore, the perspectives of caregivers of children with HIV/Aids who do not receive medical services from these hospitals were not captured. However, maximum variation was used to make sure participants with varied experienced were included in the study. Through in-depth interviews the study generated rich data that are important in understanding the play of children with HIV/Aids from the perspectives of caregivers.

4.9 Conclusion

Being HIV positive, along with contextual factors such as poverty, and limiting cultural beliefs and values are barriers to engagement in play. Play however, is a useful resource for children with HIV/Aids as it has the potential to reduce the effects of stigma and generate new meaning in life to both the child and the caregiver. Occupational therapists in paediatric practice need to be constantly aware of contextual factors that affect engagement and participation in play of children with HIV/Aids. This study affirms the role of occupational therapy in promoting play in collaboration with caregivers of children with HIV/Aids in a low resourced setting. Further studies on contextually based interventions to promote play occupations of children with HIV/Aids need to be conducted.

4.10 Key Findings from the study.

1. Play, like any other human occupation is contextually situated.
2. Children with HIV/Aids will benefit from occupational therapy.

4.11 What has the study added?

The study informs readers about play for children with HIV in low-resourced settings from caregivers' perspectives, highlighting the contextually situated nature of human occupation and practice.

4.12 References

1. Bradshaw, C., Atkinson, S., & Doody, O. (2017). Employing a qualitative description approach in health care research. *Global qualitative nursing research, 4*, 2333393617742282. doi:https://doi.org/10.1177/2333393617742282
2. Cordier, R., Bundy, A., Hocking, C., & Einfeld, S. (2009). A model for play-based intervention for children with ADHD. *Australian Occupational Therapy Journal, 56*(5), 332-340. doi:https://doi.org/10.1111/j.1440-1630.2009.00796.x
3. Cutchin, M. P., Aldrich, R. M., Bailliard, A. L., & Coppola, S. (2008). Action theories for occupational science: The contributions of Dewey and Bourdieu. *Journal of occupational science, 15*(3), 157-165. doi:https://doi.org/10.1080/14427591.2008.9686625
4. Cutchin, M. P., & Dickie, V. A. (2013). Transactional perspectives on occupation: An introduction and rationale. In *Transactional perspectives on occupation* (pp. 1-10): Springer.
5. Dender, A. M., & Stagnitti, K. (2015). Children's play in the Australian Indigenous context: the need for a contemporary view. *International Journal of Play, 4*(1), 3-16. doi:https://doi.org/10.1080/21594937.2014.977036
6. Dickie, V., Cutchin, M. P., & Humphry, R. (2006). Occupation as transactional experience: A critique of individualism in occupational science. *Journal of occupational science, 13*(1), 83-93. doi:https://doi.org/10.1080/14427591.2006.9686573
7. Fogelberg, D., & Frauwirth, S. (2010). A complexity science approach to occupation: Moving beyond the individual. *Journal of occupational science, 17*(3), 131-139. doi:https://doi.org/10.1080/14427591.2010.9686687
8. Hammell, K. R. W., & Iwama, M. K. (2012). Well-being and occupational rights: An imperative for critical occupational therapy. *Scandinavian journal of occupational therapy, 19*(5), 385-394. doi:https://doi.org/10.3109/11038128.2011.611821
9. Hocking, C. (2020). Occupation in context: A reflection on environmental influences on human doing. *Journal of occupational science*, 1-14. doi:https://doi.org/10.1080/14427591.2019.1708434
10. Hutchings, J., & Potterton, J. (2014). Developmental delay in HIV-exposed infants in Harare, Zimbabwe. *Vulnerable children and youth studies, 9*(1), 43-55. doi:https://doi.org/10.1080/17450128.2013.778440
11. Joint United Nations Programme on, H. A. (2015). Fact sheet 2015. *Geneva, Switzerland: UNAIDS*.
12. Kimbro, R. T., & Schachter, A. (2011). Neighborhood poverty and maternal fears of children's outdoor play. *Family relations, 60*(4), 461-475. doi:https://doi.org/10.1111/j.1741-3729.2011.00660.x
13. Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *American journal of occupational therapy, 45*(3), 214-222.

14. Kuo, A. (2011). A transactional view: Occupation as a means to create experiences that matter. *Journal of occupational science, 18*(2), 131-138. doi:https://doi.org/10.1080/14427591.2011.575759
15. Leadley, S., & Hocking, C. (2017). An occupational perspective of childhood poverty. *New Zealand Journal of Occupational Therapy, 64*(1), 23.
16. Lynch, H., & Moore, A. (2016). Play as an occupation in occupational therapy. In: SAGE Publications Sage UK: London, England.
17. Manjengwa, J., Matema, C., & Tirivanhu, D. (2016). Understanding urban poverty in two high-density suburbs of Harare, Zimbabwe. *Development Southern Africa, 33*(1), 23-38.
18. Milteer, R. M., Ginsburg, K. R., & Mulligan, D. A. (2012). The importance of play in promoting healthy child development and maintaining strong parent-child bond: Focus on children in poverty. *Pediatrics, 129*(1), e204-e213. doi:https://doi.org/10.1542/peds.2011-2953
19. Mlambo, T., Jelsma, J., Rusakaniko, S., Dale, N., & Chingono, A. (2017). Predictors of Zimbabwean children's neuro-cognitive performance on the Detroit Tests of Learning Aptitude fourth edition (DTLA-4): Implications for policy, practice and research. *World Federation of Occupational Therapists Bulletin, 73*(2), 94-106. doi:https://doi.org/10.1080/14473828.2017.1315500
20. Moore, A., & Lynch, H. (2018). Understanding a child's conceptualisation of well-being through an exploration of happiness: The centrality of play, people and place. *Journal of occupational science, 25*(1), 124-141. doi:https://doi.org/10.1080/14427591.2017.1377105
21. Munambah, N., Cordier, R., Speyer, R., Toto, S., & Ramugondo, E. L. (2020). A Systematic Review Comparing the Play Profiles of Children with Special Health Care Needs with Typically Developing Children. *BioMed Research International, 2020*.
22. Patton, M. Q. (1990). *Qualitative evaluation and research methods*: SAGE Publications, inc.
23. Potterton, J., Stewart, A., Cooper, P., Goldberg, L., Gajdosik, C., & Baillieu, N. (2009). Neurodevelopmental delay in children infected with human immunodeficiency virus in Soweto, South Africa. *Vulnerable children and youth studies, 4*(1), 48-57. doi:https://doi.org/10.1080/17450120802183728
24. Ramugondo, E. L. (2012). Intergenerational play within family: The case for occupational consciousness. *Journal of occupational science, 19*(4), 326-340. doi:https://doi.org/10.1080/14427591.2012.710166
25. Ramugondo, E. L. (2015). Occupational consciousness. *Journal of occupational science, 22*(4), 488-501. doi:https://doi.org/10.1080/14427591.2012.710166
26. Ramugondo, E. L., Galvaan, R., & Duncan, E. (2015). Theorising about human occupation. *South African Journal of Occupational Therapy, 45*(1), 1-2.
27. Ramugondo, E. L., & Kronenberg, F. (2015). Explaining collective occupations from a human relations perspective: Bridging the individual-collective dichotomy. *Journal of occupational science, 22*(1), 3-16. doi:https://doi.org/10.1080/14427591.2013.781920
28. Rodger, S., Ashburner, J., Cartmill, L., & Bourke-Taylor, H. (2010). Helping children with autism spectrum disorders and their families: Are we losing our occupation-centred focus? *Australian Occupational Therapy Journal, 57*(4), 276-280. doi:https://doi.org/10.1111/j.1440-1630.2010.00877.x
29. Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in nursing & health, 23*(4), 334-340.

30. Skard, G., & Bundy, A. C. (2008). Test of playfulness. In *Play in occupational therapy for children* (pp. 71-93): Elsevier.
31. Whiteford, G. (2000). Occupational deprivation: Global challenge in the new millennium. *British journal of occupational therapy, 63*(5), 200-204. doi:https://doi.org/10.1177/030802260006300503
32. Wilcock, A. A. (2007). Occupation and health: Are they one and the same? *Journal of occupational science, 14*(1), 3-8. doi:https://doi.org/10.1080/14427591.2007.9686577

5 CHAPTER 5: Delphi Study

5.1 Introduction

This chapter presents findings from a Delphi study that was conducted to gain consensus on components to include in the play-based intervention framework developed to promote play of children with HIV/Aids. By synthesising the findings from chapters 2-4, the play-based interventions framework was formulated and presented for expert opinions on the components of the play-based intervention. Based on their professional knowledge and experience, viewpoints from experts provide an important oversight of the play-based intervention framework. This chapter starts by giving background information on the study and the research questions posed in this study. The methodology and the findings will be shared. The chapter concludes with a discussion of the findings and the proposed implications for future practice.

This chapter is a journal manuscript submitted to the Scandinavian Journal of Occupational Therapy. The manuscript is currently under review. The article is presented as Microsoft Word document and has been formatted according to the Scandinavian Journal of Occupational Therapy guidelines. A list of references for this chapter is presented at the end of the chapter.

5.2 Background Information

Play has been recognised as an important part of child development (Gerlach et al., 2014). Through play children learn and develop fundamental motor, cognitive and socio-emotional skills (Lynch et al., 2016). Play forms a platform for children to learn survival skills, to build resilience in dealing with difficult life events, and to develop self-efficacy and adult life skills (Milteer et al., 2012). In the context of HIV/Aids, children are likely to have developmental delays and disabilities which pose a risk to performance in meaningful play activities. A study by Brassell and Potterton (2019) listed common disabilities in children with HIV/Aids as developmental delays, communication difficulties, cognitive deficits and physical disabilities, which affect children's engagement in play and school activities. Some children with HIV/Aids are likely to fatigue easily and will have difficulty in engaging in prolonged physical play.

Prior to this Delphi study, Munambah, Cordier, Chiwaridzo, et al. (2020) carried out a research study using the Test of Playfulness to compare the level of playfulness of children with HIV/Aids against typically developing children in Zimbabwe. The study revealed that generally children with HIV/Aids were less playful outdoors as compared to age and gender matched typically developing children. Due to fear of stigma, caregivers tend to also overprotect the child, making it difficult for the child to have control over their own play (Munambah, Gretschel, et al., 2020). Children with HIV/Aids are also likely to experience difficulty in negotiating with others, supporting the play of others and sharing ideas and objects with others (Munambah, Cordier, Chiwaridzo, et al., 2020). In the study by (Munambah, Cordier, Chiwaridzo, et al., 2020), these children also performed poorly on freedom to suspend reality items such as extent and skill of pretending and extent and skill of using people/objects unconventionally. These findings point to a need for play-based interventions for children with HIV/Aids.

5.3 Conceptual framework: Model of children's play

A descriptive model of children's play by (Cooper, 2000) can be used as a workable way of conceptualizing the underlying skills and behavioural elements characteristic of play, and the influences that both individual and environmental factors have on play. In this model, Bundy's definition is used to define play as "…a transaction between an individual and the environment that is intrinsically motivated, internally controlled and free of many of the

constraints of objective reality…" (Skard & Bundy, 2008, p. 71). During play, the individual child brings developmental abilities (cognitive, motor, language and social skills) along with his or her personal play preferences and level of playfulness (internal control, freedom to suspend reality, intrinsic motivation and framing) to the play transaction, while the environment (physical environment and cultural milieu) either encourages or limits play activities (Cooper, 2000).

In order to successfully engage in play, a child's own level of playfulness and developmental skills need to match the play task and environmental demands (Ramugondo et al., 2018). This means that play is partially dependent on the achievement of certain developmental skills such as gross motor skills that a child may use to play. For example, when children engage in physical activity, they may require adequate eye-hand coordination, locomotion and manipulation skills which enhance play performances. Cognitive play skills which include problem solving skills and logical reasoning skills will enable a child to use play materials in a more adaptive and elaborate manner (Cooper, 2000). Proficient social play skills underpin the child's ability to communicate and engage with peers during play (Barnes et al., 2017). Thus, a persistent mismatch between a child's developmental skill level, playfulness, and environment may lead to withdrawal from play opportunities (Ramugondo et al., 2018).

Playfulness is a key aspect of play to explore in children with impairments. This construct focuses on the quality of play and the adaptability and coping mechanisms of a child, regardless of ability (Hamm, 2006). Playfulness goes beyond just the actual play scenario, to consider the child's disposition to play and relates to a child's ability to cope in later life (Skard & Bundy, 2008). The construct of playfulness comprises of four fundamental elements: intrinsic motivation, internal control, the freedom to suspend reality, and framing (Skard & Bundy, 2008). Internal control suggests that the child is largely in control of his or her actions and some aspect of the activity's outcome (Hamm, 2006). This element may be observed through traits such as the child's ability to determine what happens and how or with whom she or he is playing (Bundy, 1997). Freedom to suspend reality refers to the child's ability to introduce non literal, pretend elements into play (Bundy, 1997). Here, the player is not bound by unnecessary constraints of reality and usual meanings of objects cease to apply (Cordier et al., 2010c). For example, a child may use a brick as a car; driving it and stopping to pick up passengers (these could be sticks). Intrinsic motivation refers to some unnamed aspect of the play activity, rather than to an external reward (Bundy et al., 2001) for playing.

Framing refers to the ability to appropriately give and read play cues from the environment and other playmates (Pearton et al., 2014). Responding to playmates appropriately requires an adequate understanding of social rules, which allows the player to reciprocate playmates during play (Barnes et al., 2017; Cordier et al., 2009). Some children with HIV/Aids have challenges in communicating with others, often stemming from hearing impairments (Brassell & Potterton, 2019). This poses a challenge for these children when trying to give cues or to respond to cues during play.

Apart from the child's abilities, the context in which play happens has potential to either promote or limit performance in the play of children with HIV/Aids. In the model of children's play by (Cooper, 2000), the context is referred to as both the child's immediate environment (physical setting, available play materials and social elements) and the surrounding cultural values and beliefs. A study done in Zimbabwe with caregivers of children with HIV-related neurodevelopmental delays revealed that cultural and spiritual beliefs, as well as fear of stigma impacts on how caregivers support and influence the play of their children (Munambah, Gretschel, et al., 2020). Stigma, coupled with poverty adds to the burden of caring for a child with HIV/Aids in low resourced settings (Steinert et al., 2017).

5.4 Play-based interventions

Although occupational therapists acknowledge the centrality of play occupation for children, not much focus has been taken on developing evidence-based interventions to promote play in children. Most psycho-social interventions have been criticised for not addressing play as an outcome (Wilkes-Gillan et al., 2016). Few intervention studies that focused on play as an outcome include a play-based intervention for children with ADHD (Cordier et al., 2009) with Wilkes-Gillan et al. (2016) pilot testing that intervention. Similarly another play-based intervention was developed for children with ASD (Henning et al., 2016). Stagnitti et al. (2012) conducted a learning-to-play program in schools. In South Africa, a play-informed, caregiver-implemented, home-based intervention (PICIHBI) was developed with the aim of promoting play of children with HIV/Aids (Ramugondo et al., 2018). The emphasis of the intervention was however on capacitating the caregiver to promote play in children with HIV/Aids and not directly on the children's ability to play.

The development of an evidence based play-based intervention is considered as a complex, often costly and time intensive process (Henning et al., 2016). The United Kingdom's (UK)

Medical Research Council (MRC) has developed guidelines to provide some structure for the development of complex interventions (Campbell et al., 2007; Craig et al., 2013). These guidelines emphasise a systematic phase-based approach to research starting from a theoretical phase, then pilot trials and later to controlled definitive random control trials which have the potential to be implemented in the community (Wilkes-Gillan et al., 2016). Applying the UK MRC Framework for development and evaluation of complex interventions, this paper aims to report on the findings from consultations with experts through a Delphi Study which was conducted as part of the theoretical phase of developing a framework for a play-based intervention for children with HIV/Aids living in low resourced settings.

Towards a framework for promoting play for children with HIV/Aids in a low-resourced setting, this current study employed a Delphi technique involving experts in the area of child development, play and/ or HIV/Aids with the aim of developing guidelines for a play-based intervention for children with HIV/Aids in low resourced settings. The following research questions were asked:

1. What is the theoretical framework applicable to the development of a play-based intervention for promoting play of children with HIV/Aids living in low resourced settings?

2. What treatment principles should be included in the play-based intervention for promoting play of children with HIV/Aids?

3. What active ingredients/techniques should be included in the play-based intervention for promoting play of children with HIV/Aids?

5.5 Methodology

Ethical approval was obtained from the University of Cape Town (HREC REF 640/2017) as well as from the Medical Research Council of Zimbabwe (MRCZ REF A/2364) and Joint Research and Ethics Committee (JREC REF 163/18).

5.5.1 *Study Design*

The Delphi technique was used in this study to build consensus through a series of questionnaires to a panel of selected experts (Hsu & Sandford, 2007) in the field of play,

child development and/or HIV/Aids. The Delphi technique was chosen as it allows individuals from diverse locations and fields to give their opinions without influencing or overriding one another (Boulkedid et al., 2011).

5.5.2 *Participants and Recruitment*

During the Delphi process, selection of the appropriate participants is important as this directly affects the quality of data to be generated (Boulkedid, Abdoul, Loustau, Sibony, & Alberti, 2011). Participants were selected based on having at least 5 years' experience of work in the professional field selected, with a demonstrable track-record of working with children. The experts included clinicians, educators, researchers from the professional fields of occupational therapy, physiotherapy, speech and language therapy, education, psychology, medicine and academia. Being knowledgeable about play and the use of play as a medium for intervention in children, having expertise on how HIV/Aids affects children's functional ability, or having worked with children in low resourced areas were some of the inclusion criteria used. Experience in dealing with children's issues, as well as in developing guidelines for interventions was also considered. The authors came up with a list of the proposed experts based on the professional categories above. Some recruited experts were asked to identify other potential experts. Because the experts were from diverse locations and areas of expertise (Boulkedid et al., 2011) on online survey and emails were used for communication. For the Delphi to be successful, it was important that participants be willing and committed to making valuable contributions of their expertise (Hsu & Sandford, 2007). Thus, an email was sent to all the identified experts explaining the study, including timelines as well as inviting them to take part in the study. These experts were asked to accept or decline taking part in the study and to confirm their availability and willingness to revise their responses as the Delphi process unfolded. Experts who responded and showed willingness to take part in the study were sent an informed consent form which they were requested to sign and return. Telephone calls were made for follow-up whenever necessary.

5.5.3 *Procedures*

The primary author facilitated the Delphi in collaboration with the other authors. All Delphi rounds were piloted with individuals with relevant experience including teachers, academics and clinicians to check on the clarity of questions and the response burden on participants prior to rollout. Theoretically, the Delphi process can be continuously iterated until

consensus is determined to have been achieved (McPherson et al., 2018). Two Delphi rounds were planned for and these were conducted between April and August 2020. Round one involved open- and close-ended questions and round two included mostly close-ended questions. For close-ended questions, experts were required to rate their level of agreement or importance of items on a 5-point Likert scale (i.e., 1 meaning "strongly agree" or "very important" and 5 meaning "strongly disagree", or "not important"). Experts who responded "neutral", "disagree" or "strongly disagree", "of little importance" or "not important" to any of the questions were asked to provide their reasoning. Qualtrics software was used to design and generate the questionnaire as well as follow up emails. The Qualtrics is an online data collection and analysis survey application that can be accessed using any web browser or operating system (Snow & Mann, 2013). On the first page of the survey, experts were provided with study details and were asked to confirm consent to participation in the study prior to accessing the rest of the survey. The link to the questionnaire was then emailed to the experts and remained accessible for 3 to 5 weeks. It took approximately 30 to 45 minutes to complete each survey. A reminder was sent to all experts who had not yet finished the survey one week prior to the due date.

5.5.3.1 Round One:

Based on the literature review and previous research studies on play profiles of children with HIV/Aids (Munambah, Cordier, Chiwaridzo, et al., 2020), a survey questionnaire was developed for the first round of the Delphi study. The survey questionnaire was reviewed by two experts in the field of play research. Feedback given was mainly to change the way some questions where structured as well as adding more details on the instructions to make it clearer for the respondents. The survey included three parts. The first part included the demographics and professional backgrounds of the experts. The second part asked questions relating to the application of the model of children's play (Cooper, 2000) to children with HIV/Aids. The third part asked experts to share some of the challenges that have potential to limit play and some of the techniques that can be used in promoting play of children with HIV/AIDS.

To assist them in responding to the survey, experts were provided with a reference document, which explained the Children's play model and its application to children with HIV/Aids (see supplementary doc 1). The first round helped to establish whether experts felt constructs depicted in the children's play model were relevant, appropriate and applicable to children

with HIV/Aids as well as to determine whether these constructs should be a focus of the play-based intervention. Experts were encouraged to contact the primary author if they had any feedback, queries or concerns. After collection of the experts' responses, the data were extracted and analysed. Feedback on information gathered was given to experts before the second round. Feedback is necessary in the Delphi process as it helps experts to review their responses in relation to other experts (Boulkedid et al., 2011). Findings from round one of the Delphi were used to develop a questionnaire that was used in the second round.

5.5.3.2 Round Two:

The second round focused on gaining expert consensus on the content, delivery and feasibility of the play-based intervention guidelines for children with HIV/Aids living in low resourced settings. A questionnaire based on findings from stage one and the literature review was sent out to all the experts. This time the questionnaire had mainly close-ended questions. Experts were asked to review the summary of findings from the first round and to rank the responses, thereby establishing preliminary priorities. Also in round two, experts were asked about the structure, frequency and intensity of both pre-intervention learning and the play-based intervention. At the end of round two, experts were sent a summary of results and informed that a third and final round was not required, as consensus had been achieved. Experts were sent a document with a summary of the findings from round two with an outline of how the findings would inform the development of the play-based intervention.

5.5.4 *Data Analysis*

The Delphi process involved both quantitative and qualitative data. Quantitative data were analysed using descriptive statistics; qualitative data were analysed using content analysis. Survey responses were imported onto the Statistical Package for the Social Sciences (SPSS) (IBM Corporation, 2015) software version 26 and anonymized prior to analysis. Criteria used for establishing consensus were determined prior to the study, based on Delphi literature (Boulkedid et al., 2011). Consensus was reached when at least 70% or more of experts selected "agree" or "strongly agree" or "important" or "very important" on Likert scale questions (i.e., a median score of 1 or 2 on a 5-point Likert scale and an inter-quartile range (IQR) of 1) on each item.

Participant responses to open-ended questions were analysed using conventional qualitative content analysis (Graneheim & Lundman, 2004). This process involved identifying meanings

in participant comments and coding each comment by assigning a descriptor. These descriptive codes were considered alongside quantitative data on an excel spreadsheet to help develop subsequent survey rounds and identify reasons for lack of consensus.

5.6 Results

5.6.1 *Demographics of the participants*

Invitations were sent out to 87 experts and 50 responded. Of the experts who responded, 13 did not complete the survey and their data were removed from analysis. Data from the remaining 37 experts were available for analysis in the first round. In round two 35 experts responded to the survey giving a response rate of 94.6%. Table 5.1 presents the demographic data of experts who completed the first and the second round of the Delphi study.

Table 5.1: Demographic details of experts

	Round 1		**Round Two**	
Participant Demographic Information	N	%	N	%
Gender				
Male	8	21.6%	7	20.0%
Female	27	73.0%	26	74.2%
Preferred not to say	2	5.4%	2	5.7%
Age (years)				
20-29 years	4	10.8%	4	11.4%
30-39 years	13	35.1%	12	34.2%
40-49 years	5	13.5%	5	14.3%
50-59 years	7	18.9%	7	20%
60-69 years	6	16.2%	5	14.3%
70-79 years	2	5.4%	2	5.7%
Country of residence				
Australia	8	21.6%	7	20%
Malawi	3	8.1%	3	8.6%
Bermuda	1	2.6%	1	2.9%
Ireland	1	2.6%	1	2.9%
South Africa	7	18.9%	7	20%
United Kingdom	2	5.4%	2	5.7%
United States of America	6	16.2%	5	14.3%
Zimbabwe	9	24.3%	9	25.7%
Highest qualification				
Bachelor (or equivalent) degree	13	35.2	13	37.1%
Master's degree, please specify	10	27.0%	10	28.6%
PhD	14	31.8%	12	34.3%
Professional role				
Occupational therapist	21	38.1%	20	57.1%
Researcher/ academic	14	25.5%	13	37.1%
Educationalist (including teachers)	8	14.5%	8	22.8%
Speech and Language therapist	4	7.3%	4	11.4%
Psychologist	4	7.3%	4	11.4%
Medical Doctor (various specialty)	3	5.5%	3	8.6%
Physiotherapists	1	1.8%	1	2.9%

Employment sector				
Service Provider (i.e. hospitals)	13	25.5%	13	37.1%
University	15	29.4%	13	37.1%
Private practice/ Small business	9	17.6%	9	25.7%
Education sector	7	13.7%	7	20.0%
Currently a PhD student	7	13.7%	7	20.0%
Experience (Years)				
5 - 9 years	13	38.2%	13	37.1%
10 - 11 years	9	20.6%	8	22.9%
12 - 13 years	4	11.8%	4	11.4%
14 - 15 years	6	14.7%	6	17.1%
>15 years	5	14.7%	4	11.4%

The experts were drawn from various fields of practice including occupational therapists at 21 (38.1%), researchers at 14 (25.5%), educationalists at 8 (14.5%) and speech and language therapists at 4 (7.3%). In terms of country of residence, most experts were from Australia 8 (21.6%), followed by South Africa 7 (18.9) and then Zimbabwe 9 (24.3%).

5.6.2 *Common challenges that limit play in children with HIV/Aids*

Common challenges limiting play reported by experts with regards to children with HIV/Aids were fatigue at 30 (26.4%), not skilled enough to play at 26 (18.1%), inability to express oneself at 24 (16.7%), and lack of playmates at 24 (16.7%). Several experts went on to specify (in open ended responses) that children with HIV/Aids are likely to be exposed to limited play opportunities (mainly due to low resources), lack of encouragement or stimulation from others in their environments, lack of time to play, and may be over-protected by others in their environment. Also, time spent in hospital was cited as likely to reduce playtime for children with HIV/Aids.

5.6.3 *Application of the Children's model of play*

Most experts 28 (84.8%) agreed that the proposed model of children's play is applicable for use in promoting play for children with HIV/Aids. Some experts were of the view that not all children with HIV/Aids would show play deficits as some children are asymptomatic, hence the model may not be applicable in that case.

5.6.4 *Principles for the play-based intervention*

The percentage agreement on aspects to be included in a play-based intervention for children with HIV/AIDS was relatively high on advocacy for more play opportunities (96.2%), inclusion of culturally sensitive practice (84.4%) and increasing social interaction (84.8%). A lower percentage agreement was recorded on video modelling (33.3%), compliance to medication (57.6%), and provision of food (66.7%). These three items with a lower

percentage were given back to experts with an explanation of each one of them. Experts were asked to rate them again and the percentage agreements increased as follows; video modelling (76.5%), compliance to medication (88.2%) and provision of food (88.2%). See Table 5.2 below.

Table 5.2: Play-based intervention principles

Aspects to be considered in play-based intervention program	**Round 1**			**Round 2**		
	Median	**IQR**	**Percentage Agreement**	**Median**	**IQR**	**Percentage Agreement**
Should target Physical play skills	1	1	79.4%			
Should target Social play skills	1	2	70.6%			
Caregiver involvement	2	1	81.3%			
Peer involvement	2	2	72.7%			
Video modelling	3	2	33.3%	1	1.25	76.5%
Building resilience	1	1	81.8%			
Increase social interaction	2	1	84.8%			
Awareness campaigns (information dissemination on play)	2	1	81.8%			
Awareness campaigns (dispelling myths around HIV/Aids)	1	1	75.8%			
Psychosocial education	2	2	71.9%			
Advocacy for more play opportunities	1	0.25	96.2%			
Cultural sensitive practice about play	1	1.50	84.4%			
Compliance to medication	2	1	57.6%	1	1	88.2%
Provision of food	2	2	66.7%	1	1	88.2%

Nineteen experts from low resourced settings were asked for their opinion on some of the culturally sensitive practices to be included in play-based interventions. Indigenous games at 15 (78.9%), indigenous songs at 15 (78.9%) and provision of low-cost toys at 13 (68.4%) were reported as some of the culturally sensitive practices to be included in a play-based intervention for children with HIV/Aids. Most these experts agreed that the environment should be emotionally safe at 16 (84.2%) and physically safe at 14 (73.9%) and allow for interactions at 11 (57.9%). No participant was of the view that involving adults in the play environment was critical.

5.6.5 *Round Two*

In developing the play-based intervention, all experts were asked to rate the techniques which could be effectively used to address deficits experienced by children with HIV/Aids on the elements of playfulness (internal control, intrinsic motivation, freedom to suspend reality and framing). Peer modelling, therapist modelling and caregiver education were the most identified techniques, see Table 5.3 below.

Table 5.3: Techniques to be included in the Play-based Intervention Framework

Elements of playfulness	Items on Test of playfulness	Caregiver Education	Therapist Modelling	Peer Modelling	Video Modelling	Decentering	Giving play things	Safe Environment	Allow child to choose	Allow child to succeed	Other
Internal Control	Extent of deciding what to do	**73.5%**	64.7%	82.4%	50.0%	55.9%	44.1%	67.6%	73.5%	38.2%	Giving rewards after participation Invest time in developing relationships with the child and caregivers
	Skill of modifying task requirements	64.7%	76.5%	79.4%	58.8%	47.1%	44.1%	70.6%	55.9%	44.2%	Giving verbal cues or physical guidance (e.g., hand over hand technique) Players should not be hungry or tired (from physical activity prior to this activity)
	Skill of interacting with objects	70.6%	79.4%	67.6%	55.9%	55.9%	41.2%	64.7%	50.0%	26.5%	
	Skill of negotiating needs	61.8%	76.5%	85.3%	58.8%	41.2%	29.4%	61.8%	29.4%	14.7%	
	Skill of playing with others	55.9%	82.4%	91.2%	58.8%	52.9%	35.3%	70.6%	35.3%	26.5%	
	Skill of sharing ideas and objects	67.6%	73.5%	85.3%	67.6%	41.2%	41.2%	64.7%	38.2%	23.5%	
Freedom to suspend reality	Extent of pretending	64.7%	70.6%	70.6%	47.1%	44.1%	50.0%	55.9%	47.1%	20.6%	Allow child to individually participate and solve given tasks
	Skill of pretending	70.6%	70.6%	79.4%	64.7%	38.2%	35.3%	47.1%	32.4%	26.5%	
	Extent of using people/objects unconventionally	61.8%	70.6%	61.8%	55.9%	47.1%	38.2%	50.0%	41.2%	14.7%	
	Skill of using people/ objects unconventionally	58.8%	73.5%	67.6%	52.9%	44.1%	35.3%	47.1%	44.1%	14.7%	
Intrinsic Motivation	Intensity of persistence	50.0%	64.7%	64.7%	44.1%	32.4%	35.3%	58.8%	44.1%	35.3%	Coaching Grading activity from simple to more complex
Framing	Skill of giving cues	67.6%	79.4%	67.6%	55.9%	35.3%	29.4%	52.9%	29.4%	14.7%	
	Skill of responding to Cues	61.8%	73.5%	73.5%	55.9%	32.4%	14.7%	50.0%	20.6%	11.8%	
	Skill of being engaged	55.9%	64.7%	70.6%	61.8%	35.3%	38.2%	61.8%	47.1%	29.4%	

Notes: Therapist and peer modelling has been reported as the most common techniques that can be used to address deficits exhibited on most Test of playfulness items.

5.6.6 *The indirect intervention -learning program*

In round one, some experts also suggested that an indirect intervention- learning program be included as part of the play-based intervention. The learning program would be focussed on caregivers and their children with HIV/Aids. The learning program was suggested for a total of 3-4 sessions. Table 5.4 below presents percentage agreements on the topics to be included in the learning program.

Table 5.4: Topics to be included in the indirect intervention -learning program

Topic	**Median**	**IQR**	**Percentage Agreement**
Play in children – characteristics of play, play things and toys, benefits of play, positive outcomes and long term implications'	1	1	97%
HIV/Aids – characteristics, misunderstandings and myths, common challenges in play'	1	1	90.9%
Ways/approaches to promote play children with HIV/Aids'	1	1	87.9%
Importance of building positive relationships between home, clinic and school in ways that foster collaborative partnerships'	1	1	87.9%
Play programs and strategies to assist in individualising play programs to the needs of individual children with HIV/Aids'	2	1.5	75.8%
Implementation of the play-based intervention – (i.e. how to incorporate into existing play routines, practicing intervention principles, troubleshooting potential challenges'	1	1	81.8%

5.6.7 *Format of presentation of the learning program*

Face to face (73.5%) and workshops (61.8%) were the commonly suggested presentation formats for the learning program. Experts also recommended that the presentation format should be dependent on the audience and the time that the caregiver can attend, the time of day and context. And that it should highlight salient points, and not entail too much information at one time.

5.6.8 *Delivery of the play-based intervention*

Most experts suggested that each session of the play-based intervention should last for 31-60 minutes, and the total number of sessions be 12 sessions (full-term). However, some experts suggested that a learning program involving both the child and the caregiver together, should be offered prior to the play-based intervention, with short inputs. Others suggested that additional learning sessions should be provided intermittently once the play-based intervention has been initiated.

5.7 Discussion

This Delphi study presents new ground on play-based interventions involving children with HIV/Aids. Although play-based interventions have been developed for children with ASD (Henning et al., 2016), children with ADHD (Wilkes-Gillan et al., 2016) and children with developmental delays (Stagnitti et al., 2012), very little exists for children with HIV/Aids (Meissner et al., 2017; Ramugondo et al., 2018). Yet, the negative impact of HIV/Aids has been noted on physical, social, cognitive and academic learning, play and emotional development of infected children (Brassell & Potterton, 2019). Occupational therapy service provision to this population is becoming a necessity (Meissner et al., 2017), especially in low resourced settings where HIV/Aids prevalence is high. A need to focus on play for children with HIV/Aids is in line with the call for emphasis on the centrality of occupation in occupational therapy practice (Hocking, 2020) which pushes the boundaries to view play as both a means and ends of intervention (Cordier et al., 2009). Occupational therapists are well positioned to provide this service as they have unique expertise to understand the person, his or her occupations and environment, as well as how to enable occupational performance and participation (Rodger et al., 2010).

5.7.1 *Use of a conceptual framework*

The current Delphi study aimed to obtain consensus from experts on a children's play model to inform a play-based intervention for children with HIV/Aids. Experts who participated in the study agreed that Cooper's Model of children's play (Cooper, 2000) could be used to gain understanding of the play of children with HIV/Aids, as well as guide the development of a play-based intervention for these children. Most non-pharmacological interventions have been criticised for lacking a strong theoretical rationale and some have minimal evidence to support their effectiveness (Wilkes et al., 2011). An appropriate theoretical framework ensures the best choice of intervention that targets constructs of interests and clear research questions are asked and appropriate outcome measures are selected to test the intervention's effectiveness (Campbell et al., 2007). The process of gaining expert consensus on the theoretical rationale of an intervention helps to provide conceptual clarity and consistent use of terminology for researchers and experts (Kent et al., 2018).

5.7.2 *Principles of intervention*

Principles for a play-based intervention are important to make sure that the intervention is responsive to unique needs of children and their caregivers (Henning et al., 2016), with particular attention to context. Previous published interventions for a similar population in comparable settings had been mostly centred on prevention and provision of anti-retroviral therapy with little or no focus on play for children with HIV/Aids (Ramugondo et al., 2018). Thus, experts who participated in the current study agreed that intervention principles such as a) advocacy for more play opportunities through awareness campaigns and psycho-education b) inclusion of culturally sensitive practices and provision of food during the intervention be included. Two principles of play-based intervention; that is parent/caregiver involvement and inclusion of a regular playmate, are similar to principles for the play-based intervention developed for children with ADHD (Cordier et al., 2009; Wilkes et al., 2011). According to the UK MRC Framework, there should be continual refinement of the intervention principles as the intervention is pilot tested (Craig et al., 2013).

5.7.3 *Techniques to be used in the intervention*

Although there are many techniques which could be implored during a play-based intervention, the most common techniques that experts agreed would be appropriate include caregiver, therapist and peer modelling. Similarly techniques of peer-, therapists modelling and caregiver-education were found to be effective in improving play and social skills for children with ADHD (Wilkes-Gillan et al., 2016). However, in contrast to the study by (Wilkes-Gillan et al., 2016), during the first round most experts in this study did not agree to video-modelling technique use in promoting play in children with HIV/Aids. Concern raised by experts in this regard was the availability of resources, cognisant of low resourced context, where there is likely no provision of camera or electricity to power the gadgets. After further explanation in the second round of the Delphi, experts agreed to video modelling use as a technique. Video modelling techniques can be adapted to the needs of the caregiver as part of a complex intervention, or be implemented by others with basic instruction and equipment (Prater et al., 2012). The technology required for video modelling does not need to be sophisticated. Caregivers and therapists can record play activity using commonly accessible devices, such as their smartphone, and edit the video clips using freely available software. Despite limited resources, therapists can be creative in using basic technology around them to achieve therapy goals.

The context in which play occurs is important (Miller Kuhaneck et al., 2013; Ramugondo, 2018). Occupational therapists are increasingly becoming aware of how context shapes everyday occupation (Ramugondo, 2018). In a bid to understand the context in which the intended play-based intervention will be used, some of the experts were drawn from low resourced settings. Experts in this study agreed that the play-based intervention should be culturally sensitive as well as be physically and emotionally safe for the children. These sentiments are supported by Cordier et al. (2010b) who state that children play more in their natural context within a supportive environment which is emotionally and physically safe. The physical environment (includes the space, objects) and the social context of play (play alone/with others, attitudes) are essential factors in children's play participation (Miller Kuhaneck et al., 2013).

Conducting a learning program aimed at imparting knowledge to the caregivers about play and how to promote play in their children was viewed as important by experts in the current study. The learning program would ensure continuity of skills development at home by the caregivers (Wilkes-Gillan et al., 2016). This is important especially in low resourced settings where there is usually a high therapist to client volumes with some caregivers staying long distances away from the clinic, where transport is expensive and at times rarely available. Caregivers can support and facilitate their children's play by creating more opportunities for play through restructuring time and space for play and providing the necessary resources (Rodger et al., 2010).

However, of note in the current study is that experts from low resourced settings agreed that adults should not be directly part of the play environment but rather allow children to play with their playmates. This has been echoed by caregivers from similar settings, who saw their role as mainly providing play materials and not necessarily engaging directly with their children in the play itself (Munambah, Ramugondo & Cordier (in press). This finding is surprising as caregivers have been reported to bring about positive outcomes when involved in the interventions for their children (Meissner et al., 2017), hence the tendency to want to directly involve them during a play session. However, it is an important consideration in designing and implementing play-based interventions because parental beliefs and cultural norms have an influence on play (Berinstein & Magalhaes, 2009).

Like the caregivers, experts also agreed that including a playmate in the play-based intervention would be important. Playmates play a crucial role in motivating and forming and

maintaining relationships with the child (Cordier et al., 2010b; Wilkes-Gillan et al., 2016). When engaging in play with their peers, children with HIV/Aids are likely to benefit from peer-learning and increased social interaction.

5.7.4 *Limitations*

Although the study included experts from a variety of countries which was satisfactory, some countries failed to be represented. The study sought to include as many experts as possible in the field of child development, play and or HIV/Aids. However, of the 83 experts invited only 50 responded and of those who responded only 37 completed the first round of the study. This major setback could have been because the Delphi study was sent out in April, when some countries were experiencing a peak of the COVID 19 pandemic. Participant dropout over rounds poses a limitation in Delphi studies (Boulkedid et al., 2011). Thus, the authors ensured few dropouts between the first and second round through sending reminders and extending the timeframes experts had to respond to each survey. The potentially stressful and mostly un-precedented time due to the COVID-19 pandemic, however, means experts who participated in this study were likely to be highly motivated and had interest in the research area.

5.8 Conclusion

In this study, a play-based intervention for children with HIV/Aids was developed through a rigorous process of gaining consensus from experts in the field of play, child development and /or HIV/Aids. Cooper's Model of children's play was found to be applicable for use as a theoretical framework to inform a play-based intervention for children with HIV/Aids. Findings from this study suggest that to increase playfulness in children with HIV/Aids in a low resourced setting the play-based intervention should target a) advocacy for more play opportunities through awareness campaigns and psycho-education to caregivers b) inclusion of culturally sensitive practices c) increasing social interaction through inclusion of peers d) physical and social active involvement of the child in play e) caregiver involvement in supporting the play of children even if not necessarily being directly involved in the play itself. Peer-, therapists-modelling and caregiver-education techniques were suggested as the most preferred techniques to be utilised. The process of drawing from experts including those from low resourced settings is crucial in designing and developing effective play-based

interventions aimed at promoting play for children with HIV/Aids. Such a process provides some confidence that the intervention is likely to be effective.

5.9 References

1. Gerlach A, Browne A, Suto M. A critical reframing of play in relation to Indigenous children in Canada. Journal of Occupational Science. 2014;21(3):243-258.
2. Lynch H, Hayes N, Ryan S. Exploring socio-cultural influences on infant play occupations in Irish home environments. Journal of occupational science. 2016;23(3):352-369.
3. Milteer RM, Ginsburg KR, Mulligan DA. The importance of play in promoting healthy child development and maintaining strong parent-child bond: Focus on children in poverty. Pediatrics. 2012;129(1):e204-e213.
4. World Federation of Occupational T. Position statement on human rights. WFOT Londres; 2006.
5. Brassell SE, Potterton J. Prevalence of disability in HIV-infected children attending an urban paediatric HIV clinic in Johannesburg, South Africa. Vulnerable Children and Youth Studies. 2019;14(2):95-115.
6. Munambah N, Cordier R, Chiwaridzo M, et al. Play profiles of children with HIV/Aids: A comparative study. Australian Occupational Therapy Journal. 2020.
7. Munambah N, Gretschell P, Sonday A. Being a mother of a child with HIV-related Neurodevelopmental Disorders in the Zimbabwean Context. South African Journal of Occupational Therapy. 2020;50(1):35-40.
8. Cooper RJ. The impact of child abuse on children's play: A conceptual model. Occupational Therapy International. 2000;7(4):259-276.
9. Skard G, Bundy AC. Test of playfulness. Play in occupational therapy for children: Elsevier; 2008. p. 71-93.
10. Ramugondo E, Ferreira A, Chung D, et al. A feasibility RCT evaluating a play-informed, caregiver-implemented, home-based intervention to improve the play of children who are HIV positive. Occupational Therapy International. 2018;2018.
11. Barnes G, Wilkes-Gillan S, Bundy A, et al. The social play, social skills and parent–child relationships of children with ADHD 12 months following a RCT of a play-based intervention. Australian occupational therapy journal. 2017;64(6):457-465.
12. Hamm EM. Playfulness and the environmental support of play in children with and without developmental disabilities. OTJR: Occupation, Participation and Health. 2006;26(3):88-96.

13. Bundy A. Play and playfulness: What to look for. Play in occupational therapy for children. 1997:52-66.
14. Cordier R, Bundy A, Hocking C, et al. Empathy in the play of children with attention deficit hyperactivity disorder. OTJR: Occupation, Participation and Health. 2010;30(3):122-132.
15. Bundy AC, Nelson L, Metzger M, et al. Validity and reliability of a test of playfulness. The Occupational Therapy Journal of Research. 2001;21(4):276-292.
16. Pearton JL, Ramugondo E, Cloete L, et al. Playfulness and prenatal alcohol exposure: A comparative study. Australian Occupational Therapy Journal. 2014;61(4):259-267.
17. Cordier R, Bundy A, Hocking C, et al. A model for play-based intervention for children with ADHD. Australian Occupational Therapy Journal. 2009;56(5):332-340.
18. Steinert JI, Cluver L, Melendez-Torres GJ, et al. Relationships between poverty and AIDS Illness in South Africa: an investigation of urban and rural households in KwaZulu-Natal. Global public health. 2017;12(9):1183-1199.
19. Wilkes-Gillan S, Bundy A, Cordier R, et al. A randomised controlled trial of a play-based intervention to improve the social play skills of children with attention deficit hyperactivity disorder (ADHD). PloS one. 2016;11(8):e0160558.
20. Henning B, Cordier R, Wilkes-Gillan S, et al. A pilot play-based intervention to improve the social play interactions of children with autism spectrum disorder and their typically developing playmates. Australian Occupational Therapy Journal. 2016;63(4):223-232.
21. Stagnitti K, O'Connor C, Sheppard L. Impact of the learn to play program on play, social competence and language for children aged 5–8 years who attend a specialist school. Australian occupational therapy journal. 2012;59(4):302-311.
22. Campbell NC, Murray E, Darbyshire J, et al. Designing and evaluating complex interventions to improve health care. Bmj. 2007;334(7591):455-459.
23. Craig P, Petticrew M. Developing and evaluating complex interventions: reflections on the 2008 MRC guidance. International journal of nursing studies. 2013;50(5):585-587.
24. Hsu C-C, Sandford BA. The Delphi technique: making sense of consensus. Practical Assessment, Research, and Evaluation. 2007;12(1):10.
25. Boulkedid R, Abdoul H, Loustau M, et al. Using and reporting the Delphi method for selecting healthcare quality indicators: a systematic review. PloS one. 2011;6(6):e20476.

26. Snow J, Mann M. Qualtrics survey software: handbook for research professionals. Qualtrics Labs, Inc. 2013.
27. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. Nurse education today. 2004;24(2):105-112.
28. Meissner RJ, Ferguson J, Otto C, et al. A play-informed, caregiver-implemented, home-based intervention for HIV-positive children and their families living in low-income conditions in South Africa. World Federation of Occupational Therapists Bulletin. 2017;73(2):83-87.
29. Hocking C. Occupation in context: A reflection on environmental influences on human doing. Journal of Occupational Science. 2020:1-14.
30. Rodger S, Ashburner J, Cartmill L, et al. Helping children with autism spectrum disorders and their families: Are we losing our occupation-centred focus? Australian Occupational Therapy Journal. 2010;57(4):276-280.
31. Wilkes S, Cordier R, Bundy A, et al. A play-based intervention for children with ADHD: A pilot study. Australian occupational therapy journal. 2011;58(4):231-240.
32. Kent C, Cordier R, Joosten A, et al. Peer-mediated intervention to improve play skills in children with autism spectrum disorder: A feasibility study. Australian occupational therapy journal. 2018;65(3):176-186.
33. Prater MA, Carter N, Hitchcock C, et al. Video self-modeling to improve academic performance: A literature review. Psychology in the Schools. 2012;49(1):71-81.
34. Ramugondo E. Healing work: intersections for decoloniality. World Federation of Occupational Therapists Bulletin. 2018;74(2):83-91.
35. Miller Kuhaneck H, Tanta KJ, Coombs AK, et al. A survey of pediatric occupational therapists' use of play. Journal of Occupational Therapy, Schools, & Early Intervention. 2013;6(3):213-227.
36. Berinstein S, Magalhaes L. A study of the essence of play experience to children living in Zanzibar, Tanzania. Occupational therapy international. 2009;16(2):89-106.

6 CHAPTER 6: Discussion and Conclusion

6.1 Introduction

This chapter provides a discussion of the thesis that aimed to contribute to the health and wellbeing of children with HIV/Aids living in low resourced settings by developing a framework for a play-based intervention for these children. Having observed a gap in occupational therapy clinical practice literature on play-based interventions for children with HIV/Aids, the UK MRC Framework was adopted. The framework is aimed at the development and evaluation of complex interventions (see Figure 6.1). The framework was deemed suitable to guide a systematic approach towards developing a play-based intervention framework for children with HIV/Aids living in a low resourced setting. Whilst Figure 6.1 is first presented in chapter 1, it is again included in this chapter for ease of reference. As earlier stated in chapter 1, the current study focused only on the development phase of the UK MRC Framework for complex interventions.

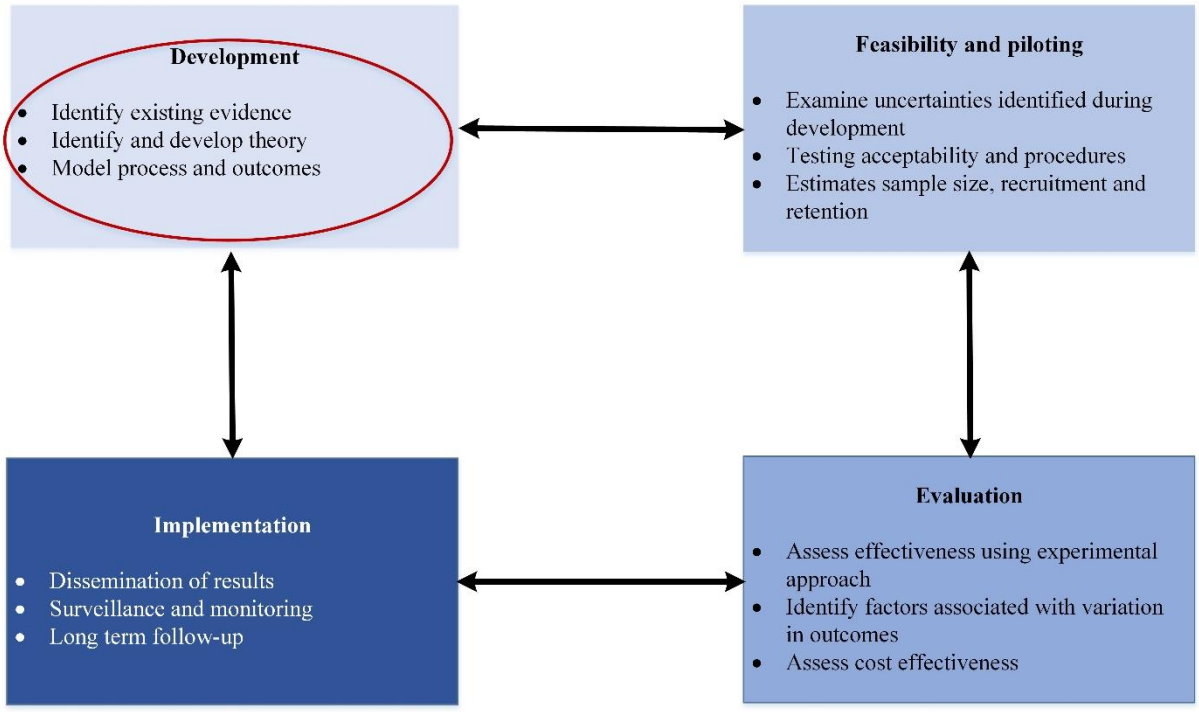


Figure 6.1: The UK MRC Framework (Craig et al., 2008)

The development phase of the play-based intervention in the current study encompassed a search for evidence that supports the need for a play-based intervention and gathering data from primary sources that included children with HIV/Aids and their caregivers, living in low resourced settings. Furthermore, expert opinion was sought through a Delphi study on what components should be included in the play-based intervention framework. This chapter

presents an overview of new knowledge generated during each stage of the intervention development process and then outlines the proposed play-based intervention framework for children with HIV/Aids living in a low resourced setting. The chapter ends with a discussion on the scope, strengths and limitations of the study, as well as implications for practice.

6.2 Developing a play-based intervention framework

Given that complex interventions are characterised by many interacting components, are sensitive to local contexts, and have practical and methodological challenges in both design and implementation (Craig et al., 2011), a thorough and robust process is needed to produce an effective complex intervention (Craig et al., 2008). Thus, the development phase of the UK MRC Framework in this study was an iterative process which started with a systematic review being conducted (chapter 2), profiling the play of children with HIV/Aids and comparing their play with typically developing children in a low resourced setting, Zimbabwe (chapter 3), and understanding the play of the children with HIV/Aids from the perspective of their caregivers (chapter 4). The final step of the process was consulting experts in the field of play, HIV/Aids and intervention development on what should be included in the play-based intervention framework in a low resourced setting (chapter 5).

6.2.1 *Identifying the evidence base*

In a bid to review the evidence on play and play-based interventions for children with SHCN, which encompass children with HIV/Aids, a systematic review was conducted. A systematic review is recommended when developing complex interventions (Craig et al., 2008; Skivington et al., 2018) as it provides a high level of evidence that provides an overview of the problem that needs intervention. Despite HIV/Aids affecting communities for a long time (Duri et al., 2013), with indications that the everyday occupation of play for these children could be affected (Mlambo et al., 2017; Ramugondo et al., 2018), there is still generally a paucity of studies that looked at the play of these children, particularly in low resourced settings. There is also, in general, limited research on play as a focus for clinical intervention in occupational therapy for children (Miller Kuhaneck et al., 2013; Moore & Lynch, 2018). A gap in literature on the play of children with HIV/Aids is of concern, especially in low resourced settings such as sub-Saharan Africa where HIV/Aids is most prevalent (Campbell et al., 2012). This gap in literature could explain why few occupational therapists are part of HIV/Aids intervention programs. Kuhaneck and Watling (2015), in their reference to services

for children with autism spectrum disorders, raise an important point that occupational therapists need to increase awareness about their role and services through service user education, research, clinical practice and advocacy.

The systematic review conducted in the current study evaluated how similar and/or different the play profiles of children with SHCN are, compared to typically developing children. Findings from the systematic review confirmed the understanding that play is broad and therefore interpreted differently across contexts (Kent, Cordier, Joosten, Wilkes-Gillan, Bundy, et al., 2020; Miller Kuhaneck et al., 2013). Research on play is thus often based on varied definitions and interpretations, which makes comparison across studies difficult. Despite not being the only professionals who use or focus on play in their interventions, occupational therapists provide a unique perspective of play as an occupation with more research necessary to substantiate this claim (Moore & Lynch, 2018).

The systematic review also found the most common standardised tool used to measure play in children with SHCN to be the Test of Playfulness, developed by Anita Bundy (Bundy, 1997; Skard & Bundy, 2008). Overall, the systematic review revealed that children with SHCN engage in less play, compared to typically developing children. This called for further studies to clearly delineate the areas of play to be targeted for specified groups of children with SHCN, such as children with HIV/Aids, and the expected changes anticipated from the intervention.

6.2.2 *Gathering further data*

Play profiles of children with HIV/Aids (Chapter 3): The theoretical phase of developing a complex health intervention is centred on understanding the nature of the health problem (Craig et al., 2008; Wilkes-Gillan et al., 2016). In this study, an understanding of play by profiling the play of children for which the intervention is intended was sought. A focus on play for children with HIV/Aids is consistent with the thrust of occupation centred occupational therapy practice which implores for a deeper understanding of the everyday doing of people (Wilcock, 2006), including play in children. There is, however, limited research on play as a focus for clinical intervention in occupational therapy for children (Miller Kuhaneck et al., 2013). The limited research on play is surprising given that play is used by occupational therapists as both a means and ends in everyday practice with children (Cordier et al., 2009; Lynch & Moore, 2016). Surveys conducted among occupational

therapists have revealed that the focus on play as an end goal is limited in practice (Miller Kuhaneck et al., 2013; Moore & Lynch, 2018). Thus, there is need to continuously look for ways in which occupational therapists working with children can promote play as an occupation so as to remain relevant to the needs of the population served (Ramugondo et al., 2018).

Due to the paucity of evidence on the play of children with HIV/Aids living in a low resourced setting, an observational study was carried out with the aim of understanding the play of children with HIV/Aids in Zimbabwe, by looking at how similar or different their play profiles are, compared to that of typically developing children. Findings from the study on play profiles confirmed our earlier assumption that children with HIV/Aids had low levels of playfulness, compared to typically developing children, particularly outdoor play (chapter 3). Although their outdoor play scores were significantly lower compared to typically developing children, this does not mean children with HIV/Aids were markedly playful indoors. The ToP mean measure score for outdoor play was M = 47.3 and SD = 22.6 while the indoor play score was M= 49.5 and SD = 22.7. These findings are consistent with a study conducted in South Africa which also found that generally children with HIV/Aids were less playful when compared to typically developing children (Ramugondo, 2018; Uys, 2016). Using the ToP to map the item scores on the elements of playfulness, children with HIV/Aids in the current study had difficulties mainly in areas of internal control, freedom to suspend reality and framing.

One key finding from the play profiles study (chapter 3), similar to findings by Henning et al. (2016) and Wilkes-Gillan et al. (2016) on children with ASD and ADHD respectively, was that children with HIV/Aids had challenges with social skills during play, such as the ability to negotiate, sharing of play materials, engaging in social play, giving cues, and responding to cues. Poor social skills are likely to result in children with HIV/Aids being rejected by peers, having fewer friends, and parents having difficulty supporting their children's friendships. Early intervention aimed at addressing social skills deficits in children with HIV/Aids at an earlier stage is important.

Caregivers' perspectives on the play of children with HIV/Aids (Chapter 4): Play, like any other occupation, is shaped by context (Kuo, 2011; Miller Kuhaneck et al., 2013). Generally, in practice, it is difficult to separate the occupation of play from the context where it happens. Thus, it was essential to have insights from the caregivers on contextual factors as we

developed the play-based intervention framework. This is even more important for low resourced settings where very few studies have been published in this field. Although in the earlier stage of the research, the researcher had visited the children's homes video-filming them playing in their natural settings as part of data collection on their play profiles, insights from the caregivers brought a different, yet important angle towards understanding the context in which play happens. As pointed out by Power et al. (2004), even well designed complex interventions can be flawed if particular attention is not given to the context in which the intervention is to be implemented.

Through in-depth interviews, caregivers confirmed the findings from chapter 3, that children with HIV/Aids were less playful as compared to typically developing children. Consistent with insights from Ramugondo (2004), some of the barriers to playfulness in children with HIV/Aids were the physical symptoms associated with being HIV positive, as well as environmental or contextual factors such as lack of safe spaces to play, stigma and poverty. However, in contrast to adult involvement in play-based interventions as proposed by Wilkes-Gillan et al. (2016), caregivers in the current study shared interesting insights about contextual factors that present as possible barriers to them directly playing with their children. For example, in Shona culture a child can play with grandparents, aunts and uncles but must show some restraint as a form of respect when approaching his or her parent, particularly the father. Parental beliefs influence the play of children (Lynch et al., 2016), thus, insights from the in-depth interviews were taken into consideration during the process of developing the play-based intervention.

6.2.3 *Identifying and developing an appropriate theoretical framework*

A rationale for a play-based intervention for children with HIV/Aids in low resourced settings was developed through a synthesis of evidence from the systemic review (chapter 2), evidence from play profiles of children with HIV/Aids (chapter 3), the perspectives of caregivers on the play of children with HIV/Aids (chapter 4), and was presented to experts in the field of play, HIV/Aids and intervention development. A method of consulting experts through a Delphi study was adopted as it has been widely used in occupational therapy (Sumsion, 1998). Similarly, Daud et al. (2016) used the Delphi method to understand challenges in implementing occupation-based interventions in Malaysia.

Through two Delphi survey rounds, consensus was achieved in the current study on the theoretical framework to be applied, as well as principles and techniques to be used to promote the play of children with HIV/Aids living in low resourced settings. The experts agreed that a model of children's play by Cooper (2000) was appropriate for use as a theoretical framework to guide the play-based intervention. A theoretical framework in complex interventions provides a lens to understand the problem, the likely processes of change and the possible outcomes of the intervention (Craig et al., 2013). Henning et al. (2016) adopted an intervention originally developed by Cordier et al. (2009) and implemented by Wilkes-Gillan et al. (2016) for children with ADHD, to promote social play skills of children with autism. Although the development of the Play-Informed, Caregiver Implemented Home Based Intervention (PICIHBI) for children with HIV/Aids that was implemented in South Africa was guided by Cultural Historical Activity Theory (Gretschel et al., 2015), there was no mention of any theoretical frameworks that guided the play intervention specifically. Apart from the theoretical framework, experts in the current study also reached consensus on principles and techniques of the intended play-based intervention (chapter 5).

6.3 Theoretical framework to guide the play-based intervention: Model of children's play

The earlier proposition by the researcher in chapter 1 that Cooper's Model of children's play was an appropriate theoretical framework to guide the content creation of the play-based intervention was confirmed by experts (chapter 6). Cooper's Model of children's play initially discussed in chapter 1 is also presented here for easy reference (See figure 6.2 below).

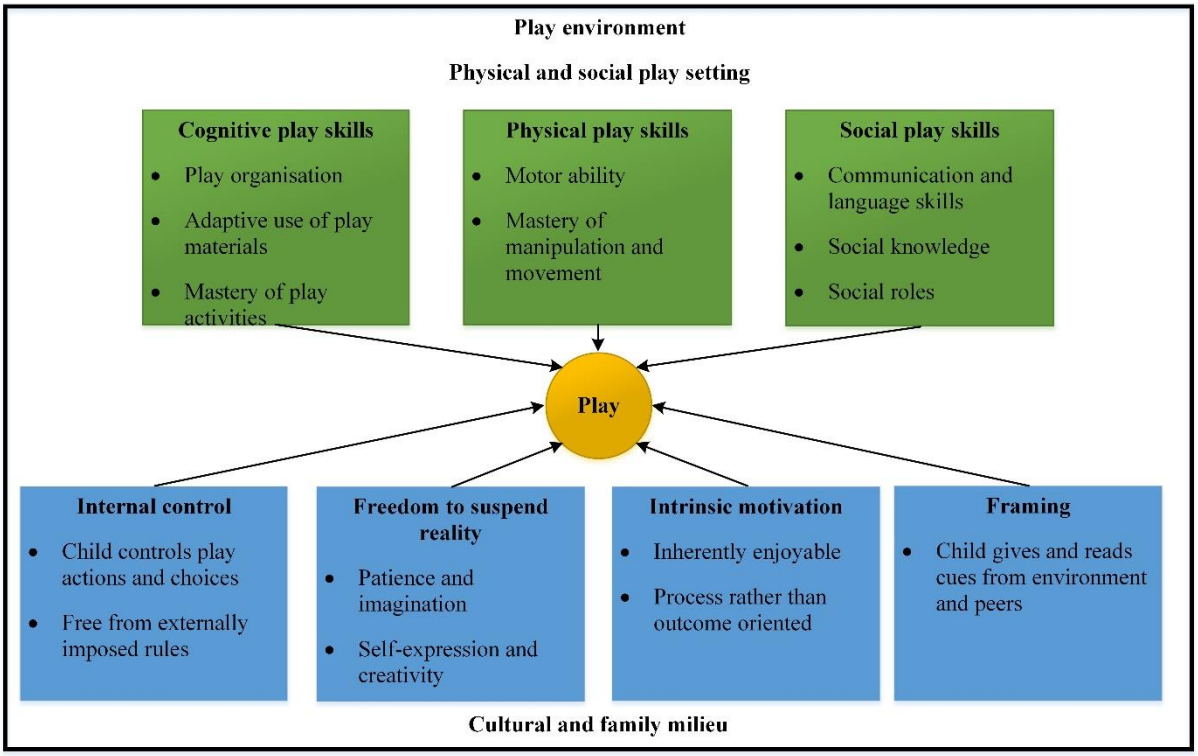


Figure 6.2: Cooper's Model of children's play (Adapted from Cooper, 2000)

Theoretical frameworks are crucial to the success of play-based interventions (Henning et al., 2016; Rodger & Ziviani, 1999). An appropriate theoretical framework is likely to result in an effective intervention as it clearly shows what changes are likely to happen (Craig et al., 2011). Although Cooper's Model of children's play was developed initially for children who have been abused, in the current study, the model was adapted for use with children with HIV/Aids in a low resourced setting.

A number of studies reported that children with HIV/Aids have deficits in child developmental capacities (i.e., cognitive, physical and social play skills) (Hutchings & Potterton, 2014; Mlambo et al., 2017; Whitehead et al., 2014). As reported in chapter 3, children with HIV/Aids in the current study expressed difficulty in some of the elements of playfulness such as internal control, suspending reality and framing. Overall, the interplay of deficits in developmental capacities and the difficulties expressed in individual play styles would likely result in reduced play. This extrapolation from Cooper's Model of children's play is confirmed by findings from chapter 3, which reported that children with HIV/Aids were less playful compared to typically developing children. A summary of these findings was presented to experts in chapter 6 through a Delphi study. Based on the data generated in this study, including opinions from experts, a play-based intervention framework was

developed. Figure 6.3 illustrates the proposed play-based intervention framework to promote the play of children with HIV/Aids living in a low resourced setting.

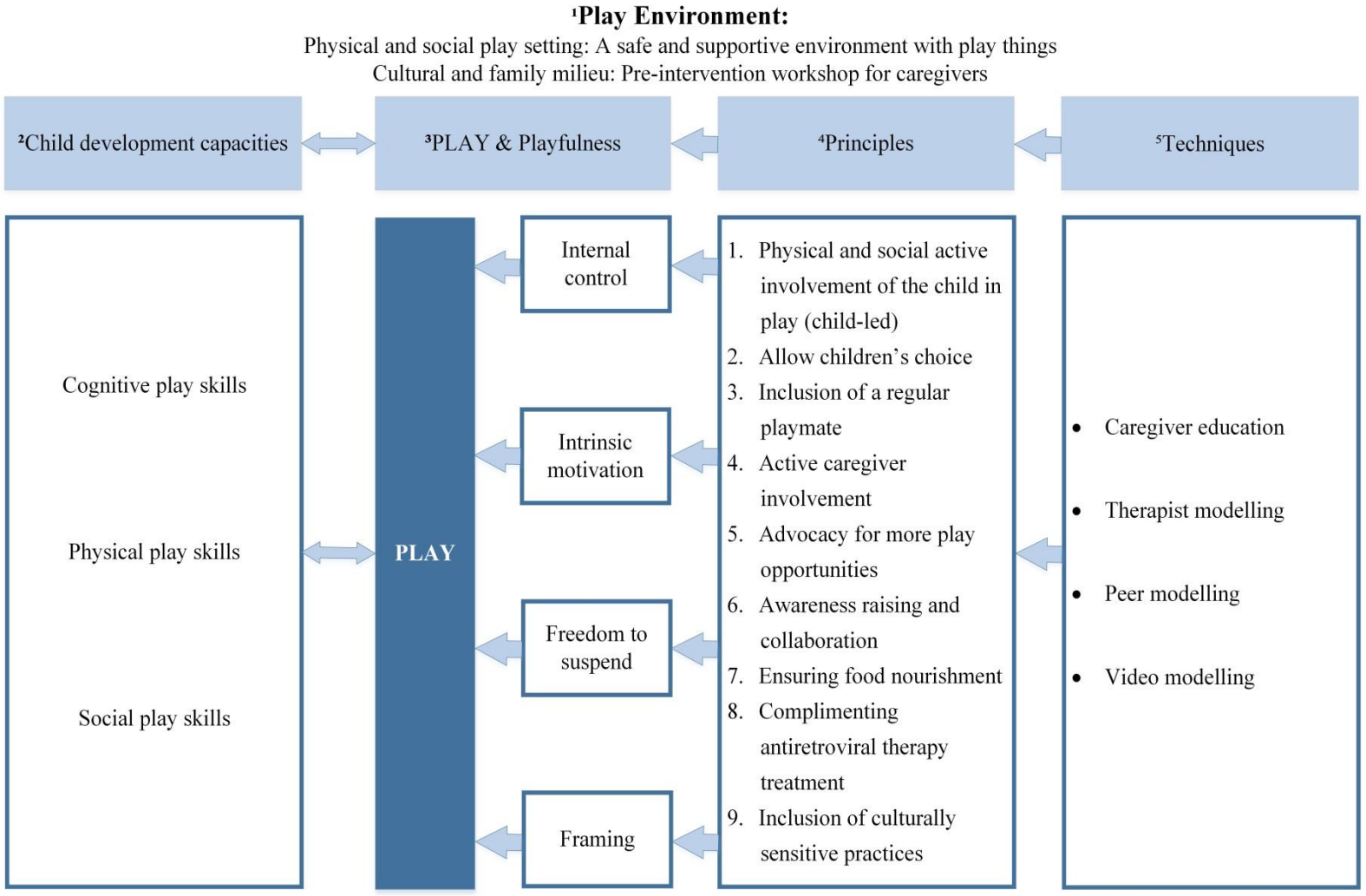


Figure 6.3: Proposed play-based intervention framework

6.4 The play-based intervention framework for children with HIV/Aids living in a low resourced setting

This play-based intervention framework for children with HIV/Aids living in a low resourced setting is based on the assumption that child-led play in a supportive context is important for child development. Play creates a platform for children to master their environment as they explore, experiment and practise new skills (Reilly, 1974). The play-based intervention framework is a complex intervention with the following 5 major interactive components: 1) the play environment, 2) child developmental capacities, 3) play features, 4) principles to promote play, and 5) techniques focused on play intervention. To promote the play of children with HIV/Aids, it is important to have an understanding of these components, including how each is related to the other. In Figure 6.3, the components of the play-based intervention framework are labelled from 1 to 5, it is in that order that each of the components is discussed below.

6.4.1 *The play environment*

The environment has potential to limit or promote play (Rigby & Gaik, 2007). As stated in chapter 4, the terms environment and context are used interchangeably in this study as is often the case in most occupational therapy literature. According to Cooper (2000), the environment consists of the physical and social environment as well as the cultural and family milieu. The physical environment includes play spaces, variety of play materials and the play site (indoors or outdoors). Generally, children play more in a safe and secure environment (Cordier et al., 2009). Thus, when implementing the play-based intervention, a safe environment with a variety of supportive play materials should be created. Techniques to address deficits noted in intrinsic motivation are centred on creating an environment that enables the child to play. To cultivate the intrinsic motivation of children such as in this study, similar to the study by (Wilkes et al., 2011), a play space that is safe and supportive of play will need to be created. A play space is not limited to a playroom or designated playgrounds, but it could be under a tree or any common space where children can come together and play.

The social environment entails the cultural and family milieu within which play occurs (Cooper, 2000). Reference to context in this study allows for consideration of other factors that impact on the society where children live. Consistent with findings by Duri et al. (2013),

most children with HIV/Aids have a low socio-economic status and live in poverty. In some of the areas where children with HIV/Aids stay, there are no playgrounds or well designated play spaces for children. In the current study, caregivers reported that the spirit of Ubuntu had been eroded resulting in some public spaces being unsafe for children to play. Occupational therapists are taught to be able to adapt the environment so as to enable participation in meaningful occupations such as play (Lynch & Moore, 2016), but are unlikely to address contextual factors such as poverty (Ramugondo, 2018). The play environment should be non-directive, nurturing and therapeutic to the child (Cooper, 2000). A naturally structured environment allows children to develop new play skills, cultivate a playful attitude and improve developmental skills (Cordier et al., 2010a).

The term play materials is preferred in this study as opposed to toys because during interviews with caregivers (chapter 4) it was noted that the term toys gave the impression of things bought mainly from shops, yet children can play with anything including bricks, sticks and emptied jars that can be locally accessed. The risk with this misconception on toys is that caregivers may fail to promote play at home in the belief that play without toys is impossible. The provision of a variety of play materials (including low cost play materials) allows children an opportunity to choose, giving them a sense of control of the play situation (Cordier et al., 2009). A study by Bartie et al. (2016) provides insights on how children in low resourced setting of South Africa used anything they found to play. This is consistent with observations during the current study, as children with HIV/Aids played around at home, most of them using locally available play materials such as sticks and used jars.

Apart from play materials, the presence of adults and other children also influence how the child responds and behaves during play (Cooper, 2000). Creating an environment that supports play is pertinent for children with HIV/Aids who have to deal with stigma that is associated with being diagnosed as HIV positive (Demmer, 2011; Munambah, Gretschel, et al., 2020). Although referring mostly to the role of technology, Ramugondo (2012) warns of some contextual factors that have potential to influence the play of children. In this study, caregivers shared how they inadvertently controlled the ‘who’, ‘what and ‘where’ of their children’s play as a way of protecting them from stigma. Most HIV infections in children are through vertical transmission (Chevo & Bhatasara, 2012). Therefore, when a child is diagnosed as being HIV positive, it is most likely that the mother is HIV positive as well. Thus, the feelings of guilt expressed by caregivers, especially biological mothers of children

with HIV/Aids, often act as a barrier to play (Ramugondo, 2004; Ramugondo, 2005). As such, the play-based intervention framework envisioned proposes a pre-intervention learning program for the caregivers, where these difficult contextual issues can be brought to the surface and engaged with.

In contrast to directly involving adults in play (Ramugondo, 2018; Wilkes et al., 2011), this study noted that caregivers, who were mostly parents and mothers to children participants, were willing to support play but not be directly involved in the play itself (chapter 4). Less cultural restriction to play was afforded to grandparents, aunts and uncles, compared to the parents, particularly the father, as primary caregivers. Apart from this cultural inclination towards play and the role of adults, this finding could also be best explained by the fact that in low resourced settings, daily occupations are centred on survival; hence it may be difficult for the primary caregiver to manage competing demands and to prioritize play. Caregivers, however, highlighted that they would want to learn more about play. Empowering caregivers with knowledge and strategies to support the play of children with HIV/Aids would foster sustainability and ensure that the intervention is continued into the home setting (Wilkes et al., 2011). This is supported by findings from the Delphi Study (chapter 5) with experts agreeing that a pre-intervention learning program for caregivers on play and ways they could support their children's play should be included as part of the program.

Generally, in low resourced settings, children are left to play on their own as adults go about their everyday work (Bazyk et al., 2003). Experts in this study agreed that the play-based intervention should include playmates that are typically developing children, so that they can play with children with HIV/Aids. These sentiments were echoed by caregivers (chapter 4) who, despite the fear of stigma, supported the idea of including (typically developing) peers as playmates. To them an opportunity for their children to play with their typically developing peers was viewed as promoting inclusivity and a vehicle to fight stigma. Including such peers in the intervention would reflect real life play contexts (Cordier et al., 2009).

6.4.2 *Child development capacities*

According to Cooper (2000), children's developmental capacities are cognitive, physical and social play skills. There is a mutual relationship between play and child development capacities where a child's play is dependent on the development and maturation of cognitive,

physical and play skills. Conversely, through play, children learn cognitive, motor, communication and social skills (Ginsburg, 2007). In some instances, when standardised tests are not available, play can be used to estimate the developmental status of a child. Children with HIV/Aids have been reported to have developmental delays in various domains such as cognitive, language, motor, and social skills (Hilburn et al., 2010; Hutchings & Potterton, 2014; Kandawasvika et al., 2015; Mlambo et al., 2017; Whitehead et al., 2014). Due to delays in the development of cognitive, language, motor and social skills, children with HIV/Aids are likely to show deficits in play (Ramugondo et al., 2018), as supported by findings from the current study (chapter 3). During play, a child explores the environment, shows some persistence in achieving tasks, and repeats some tasks until he/she masters the skill (Cooper, 2000; Cordier et al., 2009). Thus, we postulate that as children with HIV/Aids engage and participate in play and become more playful, an improvement in developmental capacities such as cognitive, physical and social skills is likely to be noted.

6.4.3 *Play and playfulness*

This play-based intervention framework is aimed at promoting the play of children with HIV/Aids living in a low resourced setting. Based on the evidence thus far, the researcher proposes that play is important for children with HIV/Aids living in a low resourced setting. Although the benefits of play in children has been widely reported (Ginsburg, 2007; Rodger & Ziviani, 1999), there has not been a universally accepted definition of play due to its broad and diverse nature (Kent, Cordier, Joosten, Wilkes-Gillan, Bundy, et al., 2020). As mentioned in earlier chapters, this study has adopted and used the widely accepted definition of play '…a transaction between the child and the environment that is internally controlled, intrinsically motivated, free from external constraints of reality and is framed by the play transaction…' (Skard & Bundy, 2008, p. 71). Play manifests itself as playfulness (Bundy, 1997) and the terms play and playfulness have been used interchangeably in much of the occupational therapy literature. Playfulness is defined as the disposition to play. Playfulness is comprised of four elements which are intrinsic motivation, internal control, freedom to suspend reality and framing. In chapter 3 the ToP was used to score the level of playfulness of children with HIV/Aids and it was noted that these children scored lower compared to age and gender matched typically developing children in the same setting, on most elements of playfulness. Similar to Cordier's model of play-based intervention for children with ADHD

(Cordier et al., 2009), the proposed play-based intervention framework in the current study will also target the elements of playfulness.

6.4.4 *Principles of the play-based intervention framework*

This section discusses nine principles for the play-based intervention framework for children with HIV/Aids living in a low resourced setting (see Figure 6.3). The principles were developed based on synthesis of the findings as reported in chapters three to five. These revealed the contextually situated nature of play for children with HIV/Aids living in a low resourced setting. Significant in this approach to play is a shift from the often-individualistic approach to play predominant in paediatric occupational therapy practice, towards principles that seek to address both individual challenges and the context of play as part of the intervention. The nine principles included in this play-based intervention framework, are 1) physical and social active involvement of the child in play (child-led), 2) allow children's choice, 3) inclusion of a regular playmate, 4) active caregiver involvement, 5) advocacy for more play opportunities, 6) awareness raising and collaboration, 7) ensuring food nourishment, 8) complimenting antiretroviral therapy treatment, and 9) inclusion of culturally sensitive practices.

Active physical and social involvement of the child: In contrast to the PICIHBI, which focussed on equipping the caregiver to implement a play informed intervention at home (Ramugondo et al., 2018), the focus of this play-based intervention framework is on the child. In highlighting the principle for physical and social active involvement of the child in play, Wilcock (2006)'s synthesis of occupation as doing, being and becoming becomes useful. Focussing on 'doing' as an important part of play as an occupation, it becomes imperative that the proposed play-based intervention creates opportunities for the child to initiate and carry out action as part of active doing. In other words, the child should be encouraged to initiate the play task, be in charge of the play to an extent that he/she can control the outcome (Cordier et al., 2009). Opportunities to be in control of play tasks counteract the challenges of overprotection and associated low self-efficacy (chapter 4). Similarly, Munambah, Gretschel, et al. (2020) reported that caregivers of children with HIV/Aids were over protective of their children by actively controlling who they play with and where to play. Opportunities for choice during play foster internal control in the child (Cordier et al., 2009; Wilkes et al., 2011).

Allow children choice: Difficulties in internal control for children with HIV/Aids could be due to over protection and over control of play by adults (Lee et al., 2013). To address this, the child should be allowed to choose what to play, how to play, whom to play with and select play materials (Cordier et al., 2009). As highlighted by caregivers in chapter 4 and experts in chapter 5, provision of a variety of play materials, which are not ready-made toys, can allow the children to select play materials of their choice. This offers opportunities for the child to also choose how to play with the play materials. For example, an empty box allows more possibilities for pretence than a ready-made car, while wooden blocks could inspire more imagination. In this case, the player is afforded more opportunities to develop the ability to suspend reality. In chapter 4, caregivers reported the use of empty jars in play and shared how they could creatively make a variety of low cost play materials from those empty jars. There are also possibilities for some communities to make home-made play materials from old tyres and wires.

Provision of a variety of play materials, especially those with open ended possibilities, would allow the child to stretch their imagination and promote creativity which is fundamental to freedom to suspend reality. Freedom to suspend reality is the ability of a child to introduce non-literal, imaginary elements into play (Bundy, 1997). Findings from this study (chapters 3 and 4) pointed to children with HIV/Aids having decreased pretence and symbolic content during play. Additionally, a variety of play materials that cater for the different genders could be included so that children can freely choose what is of interest to them.

Inclusion of a regular playmate: Through interactions with playmates, children initiate social actions, learn to solve problems cooperatively and develop pro-social behaviours like smiling and sharing play materials (Cordier et al., 2010c). Through playing with peers, children with HIV/Aids are likely to learn how to give cues, respond to cues and to be engaged in play for sustained periods of time. As mentioned earlier, involvement of typically developing playmates may be useful to break the stigma associated with HIV/Aids. In chapter 4, caregivers also confirmed that play is more fun when the child is playing with others. Although not much research has been done on playmates (Cordier et al., 2010c), involvement of playmates in the proposed play-based intervention is likely to offer opportunities for children with HIV/Aids to build and foster relationships (Wilkes-Gillan et al., 2016).

Active caregiver involvement: Cognisant that caregivers in chapter 4 reported that they need not be directly involved in play with their children but are willing to support the play of their

children, this play-based intervention includes the principle of caregiver involvement. Caregivers' willingness to be involved in the play of their children was echoed by Munambah, Gretschel, et al. (2020) who reported that caregivers of children with HIV/Aids would do everything for their child as a way of dealing with guilt and self-blame for infecting the child with HIV. Caregivers of children with HIV/Aids are, however, well positioned to encourage and foster engagement and participation of their children in play (Meissner, 2016). Similarly, in a play-based intervention focussed on children with ADHD, caregivers were instrumental in ensuring continuity of skill development even at home (Wilkes et al. (2011).

Advocacy for more play opportunities: The principle on advocacy for more play opportunities was identified based on the understanding that the value of play and psycho-social interventions has not been given much recognition in the management of children with HIV/Aids in low resourced settings (Duri et al., 2013; Ramugondo, 2004). The human rights perspective in occupational therapy implores occupational therapists to be advocates for human occupation (Townsend & Wilcock, 2004) and, as it pertains to children with HIV/Aids, to raise awareness about the need for more play opportunities. Lack of awareness and knowledge compounded by systems that are exclusionary towards people from marginalised communities could result in occupational exclusion (Pereira & Whiteford, 2013), and, in this case, lack of play opportunities for children with HIV/Aids.

If occupational therapists are to remain true to the mandate of promoting human occupation in context, they must take on an advocacy role. Empowered by policies such as the Therapists (2006) Position Statement on Human Rights which states that people have a right to engage and participate in meaningful occupations, such as play in children, and the UNCRPD Article 31 (UNICEF, 1989), which states that children have a right to play, occupational therapists are well positioned to advocate for play opportunities for children living with HIV/Aids in low resourced settings. Remaining silent, according to Townsend and Wilcock (2004), is another form of promoting occupational injustice among the populations we serve.

Caregivers in this study (chapter 4) lamented the lack of safe spaces for children to play. Engaging authorities and community leaders in a bid to advocate for a safe place for children to play is important. This may also call for developing collaborations with key stakeholders in the community to harness resources, including safe play spaces and play materials. Occupational therapists working in low resource settings can use their resourcefulness to advocate and raise funds for appropriate play materials. What is critical in such instances

would be to engage children and their caregivers about what would be appropriate and meaningful.

Awareness raising and collaborations: This play-based intervention is designed to be implemented in a low resourced setting where the medical model of practice has been dominant for a long time. Occupational therapy interventions have tended to focus on individuals, not populations, addressing performance components rather than human occupation in context. Thus, there is need for awareness rising among therapists, other health professionals, caregivers and the community, on play for children with HIV/Aids. Experts in chapter 5 suggested and agreed on including awareness raising as one of the strategies that can be used to promote the play of children with HIV/Aids. Although referring to children with ASD, Kuhaneck and Watling (2015) reported how within a team the purpose for occupational therapy can be limited to only addressing performance components such as sensory-motor issues, yet the children and their caregivers can benefit so much more from the profession. Promoting play as an occupation for children with HIV/Aids would call for awareness raising on the broad scope of occupational therapy practice for children with HIV/Aids. Awareness raising can be implemented in a variety of ways, such as informal talks during meetings with colleagues, formal meetings with various stakeholders and community leaders as well as presentations at various platforms. Providing children with HIV/Aids in Zimbabwe with antiretroviral therapy at healthcare clinics is well established practice. Raising awareness and establishing collaborations with the antiretroviral therapy team can ensure that the play-based intervention complements existing programs. Collaborations within existing programs will also allow therapists to access and benefit from using already available infrastructure and resources; an important consideration in low resourced settings. This holds true, particularly as the scope of practice in occupational therapy remains poorly defined and often misunderstood (Wilding, 2011), particularly in low resourced settings.

Ensure food nourishment: Most children with HIV/Aids in low resourced settings are likely to be living in poverty (Campbell et al., 2012). Caregivers in chapter 4 reported that providing healthy food for their children was a challenge and a major health risk as these children require well prepared healthy food to boost their immunity. This view is supported by evidence, for example, Anabwani and Navario (2005) report that provision of nutritious food is important for children with HIV/Aids as not consuming sufficient healthy food may lead to a faster progression of Aids related illnesses. While caregivers in the current study

knew about the importance of having a nutritious diet for their children, their main concern remained access. Experts in this study also agreed on the principle of providing a healthy snack to the children during play-based sessions because for children to be intrinsically motivated to play, they need to be sufficiently fed (chapter 5). When children with HIV/Aids have access to nutritious food, they are likely to be healthy and hence engage more in play. However, the link between food and play could be a key area for further research in paediatric occupational therapy.

Compliment antiretroviral treatment: The proposed play-based intervention framework is intended to be implemented in a context where children with HIV/Aids have been receiving antiretroviral therapy and the benefits of these medications have been well documented. Thus, a principle of aligning the play-based intervention framework, in such a way as to complement existing programs, like promoting compliance to medications, would promote the uptake of the intervention. Similar to findings by Munambah, Gretschel, et al. (2020), caregivers in this study reiterated the importance of being compliant with HIV/Aids medication as a way of promoting the play of children with HIV/Aids.

Inclusion of culturally sensitive practices: Some complex interventions have been reported to be ineffective or flawed due to lack of diligence in understanding the context and designing culturally sensitive implementation methods (Power et al., 2004). Unfortunately, there is little research that has been done in occupational therapy on African perspectives in understanding the play of children, including a focus on the cultural practices used to promote play for children (Berinstein & Magalhaes, 2009). Experts from low resourced settings who participated in the current study (chapter 5) suggested that indigenous games and songs, as well as low cost play materials be included in the play-based intervention. Inclusion of culturally sensitive practices in the play-based intervention allows for the children and their caregivers to connect with the intervention, which is important in building motivation and continuity. Drawing from the concept of decolonisation in relation to occupational therapy (Simaan, 2020) and occupational consciousness (Ramugondo, 2012), the proposed play-based intervention framework should be structured in such a way that children continue to engage in play in ways that are reflective of their cultural ways of thinking, doing, being and becoming. Decolonisation highlights the importance of honouring indigenous ways of knowing and doing while resisting the urge to impose potentially harmful externally driven practices that depend on global unequal relations of power between nation states and human

populations (Ramugondo, 2018). Occupational consciousness emphasises the importance of paying attention to how in everyday doing, humans either perpetuate or disrupt dominant practices, with consequences to both individual and collective well-being (Ramugondo et al., 2018; Ramugondo, 2012, 2015).

6.4.5 *Techniques/Active ingredients of the play-based intervention framework*

Techniques/active ingredients are the strategies used to promote play of children with HIV/Aids living in low resourced settings, which are based on well-developed and broadly accepted, profession or discipline specific conceptual frameworks (Parsons et al., 2019). Consistent with the findings by Henning et al. (2016), caregiver education, peer, video and therapists modelling were some of the common techniques suggested by experts in chapter 5, to be used to address deficits in the elements of playfulness. The techniques presented in this section are not exclusive to addressing one element of playfulness at any given time. They often cut across various elements of playfulness.

Caregiver Education: Similar to Wilkes-Gillan et al. (2016) and Ramugondo et al. (2018), the play-based intervention should include caregiver education as one of the techniques to achieve the goal of promoting play in children with HIV/Aids. Caregiver education would be focused on giving information to caregivers within the broader framework of adult education, on play, play materials, and strategies to promote the play of children with HIV/Aids in a low resourced setting. Caregivers in chapter 4 highlighted their willingness to learn about play, in the same manner that they have valued education on HIV/Aids and compliance to medication. Experts in this study also agreed on including a pre-intervention learning program for caregivers (Chapter 5). Caregiver education is important in promoting awareness regarding unhealthy relationships and maladaptive behaviours, thereby extending therapeutic interventions into the home environment (Wilkes-Gillan et al., 2016). Caregiver education can promote intrinsic motivation and internal control by ensuring that activities are child initiated; the child is in control of both the play activity and its outcome (Cordier et al., 2009).

Therapist modelling: This is a technique used by therapists to illustrate healthy play behaviours that service users can learn by example and practice in session (Kent, Cordier, Joosten, Wilkes-Gillan, & Bundy, 2020). The technique of therapist modelling is included on the premise that the therapist is knowledgeable about the appropriate play behaviours to be elicited during play and can promote active participation of the child with HIV/Aids. This is

critical for this population due to reported caregiver overprotectiveness. It is expected that some children with HIV/Aids may have become hesitant to engage in play. Thus, in implementing a child-led play-based intervention, therapists should be flexible and quick to identify when to adapt their approach and how to avoid always taking the lead in play (Kent, Cordier, Joosten, Wilkes-Gillan, et al., 2020). Similarly, therapist modelling has been used to redirect and promote prosocial behaviours in children with ADHD (Cordier et al., 2009). Overall, therapist modelling could be used to reinforce and consolidate all intervention strategies to promote all elements of playfulness (Wilkes et al., 2011).

Peer Modelling: Peer modelling is a technique used to provide children with the opportunity to learn skills from typically developing peers through games and activities (Wilkes et al., 2011). Similar to findings by (Henning et al., 2016) for children with autism, children with HIV/Aids who participated in this study had challenges in social skills. Some of these children had spent considerable time in hospital and were consequently unable to attend preschool. These findings are consistent with a previous study in Zimbabwe (Munambah, Gretschel, et al., 2020) where children who have HIV/Aids missed opportunities to make friends, interact and develop social skills. Peer modelling provides a platform for children with HIV/Aids to develop skills of framing through imitating actions and interacting with peers (Cordier et al., 2010c). The effectiveness of peer modelling in developing social interaction and communication has been reported in other studies that have also used play-based interventions (Henning et al., 2016; Kent, Cordier, Joosten, Wilkes-Gillan, et al., 2020).

Video-modelling: Video-modelling is a visual teaching method that occurs by watching a video of someone modelling a targeted behaviour or skill and then imitating the behaviour/skill watched. Video modelling allows for multiple skills to be captured for reflection over time and across settings, extending gains beyond the intervention period and context (Wilkes-Gillan et al., 2017). The technology required to apply video modelling does not need to be sophisticated. Therapists can record the play using commonly accessible devices, such as their smartphone, and edit the video clips using freely available software. In this study, no challenges were experienced when children were video-recorded playing with their playmates at clinics schools or at home. Thus, the therapist may video record children whilst playing and then watch the videos later with the children, discussing behaviours that promote or inhibit the play transaction, as well as future behavioural adjustments needed to

promote the play transaction. Findings reported in this thesis (chapter 3) showed that children with HIV/Aids experience significant social play deficits compared with their peers without HIV/Aids. Studies involving children with ADHD and ASD demonstrated that video modelling is beneficial in addressing social play deficits (Kent et al., 2018; Wilkes-Gillan et al., 2016). In contrast to a study by Wilkes-Gillan et al. (2017), where video-modelling was used and its benefits were noted, experts in the Delphi study (chapter 5) were initially hesitant about the appropriateness of video modelling in a low resourced setting. Experts moderated their response in favour of video modelling during the second round of the Delphi, after an explanation was given to them on how the technique was going to be used in a setting where there are limited resources. Further studies are, however, recommended on the feasibility of using this technique to improve the play of children with HIV/Aids.

6.5 Feasibility of the play-based intervention framework

Where is the intervention going to be implemented? The intervention can be implemented in multiple settings such as clinic, home and school settings. Similar studies have reported play-based interventions in the school setting (Stagnitti et al., 2016) and at the clinic (Wilkes-Gillan et al., 2014). Cognisant of the stigma associated with HIV/Aids (Demmer, 2011), the setting should be welcoming and supportive for children with HIV/Aids and their caregivers. However, further research and adaptation of the play-based intervention for use in different settings is essential so as to ensure success and maximum intervention uptake (Wilkes-Gillan et al., 2016).

Who delivers this intervention? Comparable to the play-based interventions conducted by occupational therapists (Henning et al., 2016; Wilkes et al., 2011), this play-based intervention would also be implemented by occupational therapists. However, since most of the children targeted by this intervention are school-going, teachers could be instrumental in providing some of the aspects of the intervention. Teachers have been involved in a play-based curriculum lead by occupational therapists to improve pretend play skills and oral skills among children attending their first year of formal schooling (Stagnitti et al., 2016). Although the intervention in the current study has been developed with occupational therapists in mind, teachers and community health workers can implement aspects with some training. Given the shortage of health professionals in low resourced settings, community health workers can play a critical role in health service delivery (Friedman, 2002). In Zimbabwe, community

health workers have been instrumental in implementing HIV/Aids psychosocial programs for children and adolescents (Busza et al., 2018).

Who benefits from this intervention? This play-based intervention is targeted at improving the play skills of children with HIV/Aids in a low resourced setting. The benefits of engaging and participating in play have been noted in research (Ginsburg, 2007; Lynch & Moore, 2016). As noted by Cordier et al. (2010c), playmates who also participate in the play-based intervention targeted at child populations facing health challenges benefit from the intervention as well. Caregivers in a study by Munambah, Gretschel, et al. (2020) revealed that watching their children with HIV/Aids who had once been so sick that they faced possible mortality, recovered and started to engage in play, rekindled their hope, and gave them a reason to live. Thus, apart from benefitting the child who engages in play, the value of the play-based intervention is likely to be experienced by the playmates, caregivers, and the community at large.

6.6 Scope of the research

This research focused mainly on developing a play-based intervention framework for children with HIV/Aids living in a low resourced setting. The study was centred mainly on understanding the play of children with HIV/Aids in their context and exploring areas that the intervention could focus on so that it is effective. Apart from reviewing the limited evidence from literature, the play of children with HIV/Aids in the home, school and clinic settings was observed, scored by raters blinded to the purpose of the study and the health status of individual children, and compared to that of typically developing children. Caregivers were interviewed about their perspectives of the play of their children living with HIV/Aids, and experts were consulted through a Delphi approach on the theoretical framework to be adopted, as well as principles and techniques to be included in the play-based intervention. Piloting the play-based intervention was beyond the scope of the study.

6.7 Strength and Limitations of the study

This study had strengths and limitations as outlined below.

Strengths

- As recommended by the UK MRC Framework for development and evaluation of complex interventions, the play-based intervention framework was developed from evidence gathered from literature, children with HIV/Aids, their caregivers and experts.
- The play-based intervention developed in this study is for use in a low resourced setting. As such, data collection was carried out in a low resourced setting and participants (children with HIV/Aids and their caregivers) were recruited from these settings. Some of the experts (18) who participated in this study were also working in low resourced settings. This is important as most of the literature on play originates from countries with advanced economies, whilst literature from countries with emerging market economies where resources are limited and cultural views on play are different is lacking, and play experiences can be markedly different (Gerlach et al., 2014).
- Raters who scored the Test of Playfulness videos were trained and calibrated before scoring. These raters were blinded to the purpose of the study and the health status of individual children.
- Experts with either one or both clinical and research experience informed the Delphi process. The experts were widely representative as they were drawn from across the world, including low resourced settings.

Limitations

The Delphi Study had few participants, which may have been the result of data being collected during the COVID-19 pandemic. Thus, participants could have been overwhelmed during the crisis, preventing some from participating in the Delphi Study. Conversely, those who responded are likely to have been highly motivated to participate in the study.

6.8 Recommendations for practice and education

This study is only the second such study from a low resourced setting to focus on play of children with HIV/Aids living in such settings. The study generated important information on the occupation of play for vulnerable children from a unique African perspective. Cultural beliefs shared by caregivers revealed the challenges they experience in directly engaging in play with their children, but also their willingness to support the play of these children. In practice, it is important to consider caregivers' values and beliefs, as they have potential to influence the intervention processes and therefore outcomes.

This study revealed that occupational therapists have an important role to play in the holistic management of children with HIV/Aids living in low resourced settings. Findings from this study exposed that the play of children with HIV/Aids is affected. Occupational therapists can be guided by the play-based intervention framework developed in this study to promote play and playfulness of children with HIV/aids living in low resourced settings. The model of children's play by Cooper (2000) can be used as a theoretical framework to guide the intervention.

Adopting an occupation-centred practice, where occupation is at the centre of what occupational therapists do in low resourced settings, is likely to extend practice areas, thereby widening the scope of practice for occupational therapists in low resourced settings. Also, an understanding of occupation in context calls for occupational therapists to be conscious of misconceptions that come with some terms used in everyday practice. For example, in this study, the term 'toy' was viewed by caregivers as something from the shops, yet there are possibilities of using whatever they have at their disposal to promote play at home.

Significantly, the findings point to paediatric occupational therapy practice that embraces both the individual focus, as well as a population-based approach. While the proposed intervention framework provides techniques to promote child-led play, it also offers principles that go beyond the individual child, and has potential to galvanise occupational therapists, stakeholders and whole communities into action to promote play for children with HIV/Aids in low resourced settings. Expanding the scope of practice for occupational therapy has important implications for occupational therapy education, particularly at graduate levels where occupational therapists could undertake further studies on how to provide holistic care for children with SHCN.

6.9 Recommendations for future research

According to the UK MRC Framework, a complex intervention has to be subjected to large-scale studies with robust designs or random controlled trails to determine effectiveness of the intervention before implementation in various settings (Skivington et al., 2018). However, conducting RCTs for complex interventions can be difficult because of the problems encountered during the process of developing, designing and implementation logistics of the intervention (Power et al., 2004). Thus, feasibility studies need to be conducted first to check issues to do with population, context, the intervention itself, cost related factors, and time frames (Kent et al., 2018). The feasibility studies can be used to further refine the intervention and problems identified should be addressed before conducting a large-scale study. Conducting feasibility studies is quite helpful, for example, a feasibility study by Power et al. (2004) was instrumental in the redesigning and shaping of a complex intervention on adolescent sexual health in Zimbabwe. Feasibility studies can be used to check if there are any potential problems with participant recruitment or retention, outcome measures, aspects of intervention and appropriateness of the intervention (Parsons et al., 2019). Therefore, it is recommended that future studies be carried out on the feasibility of the play-based intervention framework to promote the play of children with HIV/Aids in low resourced settings.

The UK MRC Framework recommends that these feasibility studies be carried out in a phased approach, with each feasibility study targeting key uncertainties identified during the process of developing the intervention. One area that warrants a feasibility study is on recruitment and retention of participants. In this study (chapters 3 and 4), we did not experience challenges in the recruitment of participants. This may be different during implementation of the intervention, which could be more demanding, for example, if additional visits to the clinic/play site are required. In low resourced settings the usual challenges are migration, HIV/Aids stigma, and transport issues, which can affect the recruitment and retention of participants, rendering the intervention ineffective. A study by Ramugondo et al. (2018) reported challenges in the retention of participants with some of the problems cited by caregivers being lack of transport fees, and limited time available to conduct the intervention at home.

Play in and of itself means something not serious and is often taken for granted. Implementing a play-based intervention in a setting that has been dominated by a medical

model of practice for a long time may not get the attention it deserves. Although insights on the context was drawn mostly from the caregivers (Chapter 4), experts from low resourced settings (Chapter 5) and the researcher working in a low resourced setting, a feasibility study to check the appropriateness of the play-based intervention is crucial.

This study provides a baseline for future studies on the play of children with HIV/Aids. Future studies can explore the link between food and play. Caregivers involved in this study highlighted how important it was for children with HIV/Aids to eat healthy food before play and their suggestion of including a nutritional snack as part of the intervention was agreed upon by experts. No research in occupational therapy has explored the role of food in promoting play, even in children with malnutrition in low resourced settings. Another area that could benefit from further studies is on culturally sensitive practices from low resourced settings that can be used to promote the play of children. In this study, experts recommended that the play-based intervention should include culturally sensitive practices such as traditional songs, poems and play things. However, there is little occupational therapy literature on how children living in low resourced settings play and traditional ways used to promote play in these contexts (Bartie et al., 2016; Berinstein & Magalhaes, 2009).

6.10 Conclusion

This study is the second in occupational therapy to report on the play of children with HIV/Aids. It is the first one to review and generate evidence to support play-based interventions targeted at children with HIV/Aids. Generally, children with HIV/Aids have low levels of playfulness when compared to typically developing children. Factors such as the physical symptoms associated with being HIV positive, poverty, cultural beliefs and stigma were reported by caregivers in this study as some of the barriers to play for their children. A play-based intervention framework to promote the play of children with HIV/Aids living in low resourced settings was developed in this study. The model of children's play by Cooper was confirmed to be an appropriate guiding framework for implementing the play-based intervention. The play-based intervention proposed should be child-led, allowing for choice, as well as physical and active involvement of the child. To increase social interaction and continuity into the home environment, playmates and caregivers must be included. Unique to this play-based intervention is advocacy for more play opportunities, awareness raising and collaboration, access to nutrition, complimenting antiretroviral therapy treatment and inclusion of culturally sensitive practices. Future studies

should investigate feasibility of various aspects of the play-based intervention before conducting randomised controlled trials to test the effectiveness of the intervention.

References

Alessandri, S. M. (1992, Jun). Attention, play, and social behavior in ADHD preschoolers. *J Abnorm Child Psychol, 20*(3), 289-302. https://doi.org/10.1007/BF00916693

Anabwani, G., & Navario, P. (2005). Nutrition and HIV/AIDS in sub-Saharan Africa: an overview. *Nutrition, 21*(1), 96-99.

Angelin, A. C., Sposito, A. M. P., & Pfeifer, L. I. (2018). Influence of functional mobility and manual function on play in preschool children with cerebral palsy. *Hong Kong Journal of Occupational Therapy, 31*(1), 46-53. https://doi.org/10.1177/1569186118783889

Bandura, A., & Walters, R. H. (1977). *Social learning theory* (Vol. 1). Prentice-hall Englewood Cliffs, NJ.

Bank, T. (2013). How we classify countries. *The World Bank http://data. worldbank. org/about/country-classifications. Accessed, 13*, 10-13.

Barnes, G., Wilkes-Gillan, S., Bundy, A., & Cordier, R. (2017). The social play, social skills and parent–child relationships of children with ADHD 12 months following a RCT of a play-based intervention. *Australian occupational therapy journal, 64*(6), 457-465. https://doi.org/10.1111/1440-1630.12417

Bartie, M., Dunnell, A., Kaplan, J., Oosthuizen, D., Smit, D., van Dyk, A., Cloete, L., & Duvenage, M. (2016). The Play Experiences of Preschool Children from a Low-socio-economic Rural Community in Worcester, South Africa. *Occupational Therapy International, 23*(2), 91-102.

Bazyk, S., Stalnaker, D., Llerena, M., Ekelman, B., & Bazyk, J. (2003). Play in Mayan children. *American Journal of Occupational Therapy, 57*(3), 273-283.

Beers, N. S., Kemeny, A., Sherritt, L., & Palfrey, J. S. (2016). Variations in state-level definitions: children with special health care needs. *Public Health Reports*.

Berinstein, S., & Magalhaes, L. (2009). A study of the essence of play experience to children living in Zanzibar, Tanzania. *Occupational Therapy International, 16*(2), 89-106.

Blanche, E. I. (2008). Play in children with cerebral palsy: Doing with-not doing to. *Play in occupational therapy for children*, 375-393.

Bond, T. G., & Fox, C. M. (2007). Fundamental measurement in the human sciences. *Chicago, IL: Institute for Objective Measurement*.

Boulkedid, R., Abdoul, H., Loustau, M., Sibony, O., & Alberti, C. (2011). Using and reporting the Delphi method for selecting healthcare quality indicators: a systematic review. *PloS one, 6*(6), e20476.

Boulton, M. J., & Smith, P. K. (1993). Ethnic, gender partner, and activity preferences in mixed-race schools in the UK: playground observations. In C. H. Hart (Ed.), *Children on playgrounds* (pp. 210-238). State University of New York Press.

Bradshaw, C., Atkinson, S., & Doody, O. (2017). Employing a qualitative description approach in health care research. *Global qualitative nursing research, 4*, 2333393617742282. https://doi.org/https://doi.org/10.1177/2333393617742282

Brassell, S. E., & Potterton, J. (2019). Prevalence of disability in HIV-infected children attending an urban paediatric HIV clinic in Johannesburg, South Africa. *Vulnerable Children and Youth Studies, 14*(2), 95-115.

Bronson, M. R., & Bundy, A. C. (2001). A correlational study of a test of playfulness and a test of environmental supportiveness for play. *The Occupational Therapy Journal of Research, 21*(4), 241-259.

Bundy, A. (1997). Play and playfulness: What to look for. *Play in occupational therapy for children*, 52-66.

Bundy, A. C., Nelson, L., Metzger, M., & Bingaman, K. (2001, 2001/10/01). Validity and Reliability of a Test of Playfulness. *The Occupational Therapy Journal of Research, 21*(4), 276-292. https://doi.org/10.1177/153944920102100405

Busza, J., Dauya, E., Bandason, T., Simms, V., Chikwari, C. D., Makamba, M., McHugh, G., Munyati, S., Chonzi, P., & Ferrand, R. A. (2018). The role of community health workers in improving HIV treatment outcomes in children: lessons learned from the ZENITH trial in Zimbabwe. *Health policy and planning, 33*(3), 328-334.

Cairney, J., Kwan, M. Y. W., Hay, J. A., & Faught, B. E. (2012, Sep-Oct). Developmental coordination disorder, gender, and body weight: Examining the impact of participation in active play. *Research in Developmental Disabilities, 33*(5), 1566-1573. https://doi.org/10.1016/j.ridd.2012.02.026

Campbell, C., Scott, K., Nhamo, M., Nyamukapa, C., Madanhire, C., Skovdal, M., Sherr, L., & Gregson, S. (2013). Social capital and HIV competent communities: the role of

community groups in managing HIV/AIDS in rural Zimbabwe. *AIDS care, 25*(sup1), S114-S122.

Campbell, C., Skovdal, M., Mupambireyi, Z., Madanhire, C., Robertson, L., Nyamukapa, C. A., & Gregson, S. (2012). Can AIDS stigma be reduced to poverty stigma? Exploring Zimbabwean children's representations of poverty and AIDS. *Child: care, health and development, 38*(5), 732-742. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3437489/pdf/cch0038-0732.pdf

Campbell, M., Fitzpatrick, R., Haines, A., Kinmonth, A. L., Sandercock, P., Spiegelhalter, D., & Tyrer, P. (2000). Framework for design and evaluation of complex interventions to improve health. *bmj, 321*(7262), 694-696.

Campbell, N. C., Murray, E., Darbyshire, J., Emery, J., Farmer, A., Griffiths, F., Guthrie, B., Lester, H., Wilson, P., & Kinmonth, A. L. (2007). Designing and evaluating complex interventions to improve health care. *Bmj, 334*(7591), 455-459.

Care, M. o. H. a. C. (2018). *Zimbabwe National and Sub-national HIV Estimates report 2017*.

Cattanach, A. (2004). *Introduction to play therapy*. Routledge.

Chevo, T., & Bhatasara, S. (2012, 2012/01/26). HIV and AIDS Programmes in Zimbabwe: Implications for the Health System. *ISRN Immunology, 2012*, 609128. https://doi.org/10.5402/2012/609128

Cooper, R. J. (2000). The impact of child abuse on children's play: A conceptual model. *Occupational Therapy International, 7*(4), 259-276.

Cordier, R., Bundy, A., Hocking, C., & Einfeld, S. (2009). A model for play-based intervention for children with ADHD. *Australian occupational therapy journal, 56*(5), 332-340.

Cordier, R., Bundy, A., Hocking, C., & Einfeld, S. (2010a). Comparison of the play of children with attention deficit hyperactivity disorder by subtypes. *Australian occupational therapy journal, 57*(2), 137-145.

Cordier, R., Bundy, A., Hocking, C., & Einfeld, S. (2010b). Empathy in the Play of Children with Attention Deficit Hyperactivity Disorder. *OTJR: Occupation, Participation, Health, 30*(3), 122-132. https://doi.org/10.3928/15394492-20090518-02

Cordier, R., Bundy, A., Hocking, C., & Einfeld, S. (2010c). Playing with a child with ADHD: A focus on the playmates. *Scandinavian journal of occupational therapy, 17*(3), 191-199.

Cordier, R., Bundy, A. C., Hocking, C., & Einfeld, S. (2010a). Playing with a child with ADHD: A focus on the playmates. *Scandinavian Journal of Occupational Therapy, 17*(3), 191-199.

Cordier, R., Bundy, A. C., Hocking, C., & Einfeld, S. (2010b). Empathy in the play of children with attention deficit hyperactivity disorder. *OTJR: Occupation, Participation and Health, 30*(3), 122-132.

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2008). Developing and evaluating complex interventions: the new Medical Research Council guidance. *bmj, 337*.

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2011). Developing and evaluating complex interventions. *Medical Research Council, UK*.

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2013). Developing and evaluating complex interventions: the new Medical Research Council guidance. *International Journal of Nursing Studies, 50(5), 50*(5), 587–592. https://doi.org/ https://doi.org/10.1016/j.ijnurstu.2012.09.010

Cutchin, M. P., Aldrich, R. M., Bailliard, A. L., & Coppola, S. (2008). Action theories for occupational science: The contributions of Dewey and Bourdieu. *Journal of Occupational Science, 15*(3), 157-165.

Cutchin, M. P., & Dickie, V. A. (2013). Transactional perspectives on occupation: An introduction and rationale. In *Transactional perspectives on occupation* (pp. 1-10). Springer. https://doi.org/https://doi.org/10.1007/978-94-007-4429-5_1

Dadson, P., Brown, T., & Stagnitti, K. (2020). Relationship between screen-time and hand function, play and sensory processing in children without disabilities aged 4–7 years: A exploratory study. *Australian Occupational Therapy Journal*.

Daud, A. Z. C., Judd, J., Yau, M., & Barnett, F. (2016). Issue in applying occupation-based intervention in clinical practice: a Delphi study. *Procedia-Social and behavioral sciences, 222*, 272-282.

De Santis, J. P., Florom-Smith, A., Vermeesch, A., Barroso, S., & DeLeon, D. A. (2013). Motivation, management, and mastery: a theory of resilience in the context of HIV infection. *Journal of the American Psychiatric Nurses Association, 19*(1), 36-46.

Demmer, C. (2011). Experiences of families caring for an HIV-infected child in KwaZulu-Natal, South Africa: an exploratory study. *AIDS care, 23*(7), 873-879.

Dender, A. M., & Stagnitti, K. (2015). Children's play in the Australian Indigenous context: the need for a contemporary view. *International Journal of Play, 4*(1), 3-16.

Dickie, V., Cutchin, M. P., & Humphry, R. (2006). Occupation as transactional experience: A critique of individualism in occupational science. *Journal of Occupational Science, 13*(1), 83-93.

Dominguez, A., Ziviani, J., & Rodger, S. (2006). Play behaviours and play object preferences of young children with autistic disorder in a clinical play environment. *Autism, 10*(1), 53-69.

Duri, K., Stray-Pedersen, B., & Muller, F. (2013). HIV/AIDS: The Zimbabwean situation and trends. *American Journal of Clinical Medicine Research*

1(1), 15-22. https://doi.org/DOI:10.12691/ajcmr-1-1-5

File, N. (1994). Children's play, teacher-child interactions, and teacher beliefs in integrated early childhood programs. *Early Childhood Research Quarterly, 9*(2), 223-240. https://doi.org/10.1016/0885-2006(94)90007-8

Fogelberg, D., & Frauwirth, S. (2010). A complexity science approach to occupation: Moving beyond the individual. *Journal of Occupational Science, 17*(3), 131-139. https://doi.org/https://doi.org/10.1080/14427591.2010.9686687

Friedman, I. (2002). Community based health workers: human resources. *South African health review, 2002*(1), 161-180.

Garin, O., Ayuso-Mateos, J. L., Almansa, J., Nieto, M., Chatterji, S., Vilagut, G., Alonso, J., Cieza, A., Svetskova, O., & Burger, H. (2010). Validation of the" World Health Organization Disability Assessment Schedule, WHODAS-2" in patients with chronic diseases. *Health and quality of life outcomes, 8*(1), 51.

Gerlach, A., Browne, A., & Suto, M. (2014). A critical reframing of play in relation to Indigenous children in Canada. *Journal of Occupational Science, 21*(3), 243-258.

Ginsburg, K. R. (2007). The importance of play in promoting healthy child development and maintaining strong parent-child bonds. *Pediatrics, 119*(1), 182-191.

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse education today, 24*(2), 105-112.

Gretschel, P., Ramugondo, E. L., & Galvaan, R. (2015). An introduction to Cultural Historical Activity Theory as a theoretical lens for understanding how occupational therapists design interventions for persons living in low-income conditions in South Africa. *South African Journal of Occupational Therapy, 45*(1), 51-55.

Halfon, N., & Newacheck, P. W. (2019). Evolving Notions of Childhood Chronic Illness. *Jama, 303*(7), 3-4. https://doi.org/10.1136/jech.2008.082842.16.

Halfon, S. (2017, 2017/07/03). Play Profile Constructions: An Empirical Assessment of Children's Play in Psychodynamic Play Therapy. *Journal of Infant, Child, and Adolescent Psychotherapy, 16*(3), 219-233. https://doi.org/10.1080/15289168.2017.1312875

Halfon, S., Cavdar, A., Orsucci, F., Schiepek, G. K., Andreassi, S., Giuliani, A., & de Felice, G. (2016). The Non-linear Trajectory of Change in Play Profiles of Three Children in Psychodynamic Play Therapy. *Front Psychol, 7*, 1494. https://doi.org/10.3389/fpsyg.2016.01494

Hamm, E. M. (2006). Playfulness and the Environmental Support of Play in Children With and Without Developmental Disabilities. *Occupation, Participation and Health, 26*(3), 88-96. http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.923.3626&rep=rep1&type=pdf

Hammell, K. R. W., & Iwama, M. K. (2012). Well-being and occupational rights: An imperative for critical occupational therapy. *Scandinavian journal of occupational therapy, 19*(5), 385-394.

Harkness, L., & Bundy, A. C. (2001). The test of playfulness and children with physical disabilities. *The Occupational Therapy Journal of Research, 21*(2), 73-89.

Henning, B., Cordier, R., Wilkes-Gillan, S., & Falkmer, T. (2016). A pilot play-based intervention to improve the social play interactions of children with autism spectrum disorder and their typically developing playmates. *Australian occupational therapy journal, 63*(4), 223-232.

Hestenes, L. L., & Carroll, D. E. (2000). The play interactions of young children with and without disabilities: Individual and environmental influences. *Early Childhood Research Quarterly, 15*(2), 229-246. https://doi.org/10.1016/S0885-2006(00)00052-1

Hilburn, N., Potterton, J., & Stewart, A. (2010). Paediatric HIV encephalopathy in sub-Saharan Africa. *Physical Therapy Reviews, 15*(5), 410-417.

Hocking, C. (2020). Occupation in context: A reflection on environmental influences on human doing. *Journal of occupational science*, 1-14.

Holderness, H., Chin, N., Ossip, D. J., Fagnano, M., Reznik, M., & Halterman, J. S. (2017). Physical activity, restrictions in activity, and body mass index among urban children with persistent asthma. *Annals of Allergy, Asthma & Immunology, 118*(4), 433-438.

Hsieh, H. C. (2012, Nov-Dec). Effectiveness of adaptive pretend play on affective expression and imagination of children with cerebral palsy. *Res Dev Disabil, 33*(6), 1975-1983. https://doi.org/10.1016/j.ridd.2012.05.013

Hsu, C.-C., & Sandford, B. A. (2007). The Delphi technique: making sense of consensus. *Practical Assessment, Research, and Evaluation, 12*(1), 10.

Huang, L., Freed, G. L., & Dalziel, K. (2020). Children with special health care needs: how special are their health care needs? *Academic pediatrics, 20*(8), 1109-1115.

Huang, L., Freed, G. L., & Dalziel, K. (2020). Children With Special Health Care Needs: How Special Are Their Health Care Needs? *Academic Pediatrics*, 1-7. https://doi.org/https://doi.org/10.1016/j.acap.2020.01.007

Hutchings, J., & Potterton, J. (2014). Developmental delay in HIV-exposed infants in Harare, Zimbabwe. *Vulnerable Children and Youth Studies, 9*(1), 43-55.

Ikiugu, M. N., Smallfield, S., & Condit, C. (2009). A framework for combining theoretical conceptual practice models in occupational therapy practice. *Canadian journal of occupational therapy, 76*(3), 162-170.

Joint United Nations Programme on, H. A. (2015). Fact sheet 2015. *Geneva, Switzerland: UNAIDS*.

Kandawasvika, G. Q., Kuona, P., Chandiwana, P., Masanganise, M., Gumbo, F. Z., Mapingure, M. P., Nathoo, K., & Stray-Pedersen, B. (2015). The burden and predictors of cognitive impairment among 6-to 8-year-old children infected and uninfected with HIV from Harare, Zimbabwe: a cross-sectional study. *Child Neuropsychology, 21*(1), 106-120.

Kandawasvika, G. Q., Ogundipe, E., Gumbo, F. Z., Kurewa, E. N., Mapingure, M. P., & Stray-Pedersen, B. (2011). Neurodevelopmental impairment among infants born to mothers infected with human immunodeficiency virus and uninfected mothers from three peri-urban primary care clinics in Harare, Zimbabwe. *Developmental Medicine & Child Neurology, 53*(11), 1046-1052.

Kent, C., Cordier, R., Joosten, A., Wilkes-Gillan, S., & Bundy, A. (2020). Can we play together? A closer look at the peers of a peer-mediated intervention to improve play in children with autism spectrum disorder. *Journal of autism and developmental disorders*, 1-14.

Kent, C., Cordier, R., Joosten, A., Wilkes-Gillan, S., Bundy, A., & Speyer, R. (2020). A systematic review and meta-analysis of interventions to improve play skills in children with Autism Spectrum Disorder. *Review Journal of Autism and Developmental Disorders, 7*(1), 91-118.

Kent, C., Cordier, R., Joosten, A., Wilkes-Gillan, S., & Bundy, A. (2018). Peer-mediated intervention to improve play skills in children with autism spectrum disorder: A feasibility study. *Australian occupational therapy journal, 65*(3), 176-186.

Kent, C., Cordier, R., Joosten, A., Wilkes-Gillan, S., & Bundy, A. (2020). Can I join in? Multiple case study investigation of play performance generalisation for children with autism spectrum disorder from dyad to triad. *Australian occupational therapy journal, 67*(3), 199-209.

Kharsany, A. B. M., & Karim, Q. A. (2016). HIV infection and AIDS in sub-Saharan Africa: current status, challenges and opportunities. *The open AIDS journal, 10*, 34.

Khoshali, A. K., & Venkatesan, S. (2010). Development of Play Activity Checklist for Childen with Mental Retardation. *Indian Journal of Clinical Psychology, 37*(2), 101-107.

Kimbro, R. T., & Schachter, A. (2011). Neighborhood poverty and maternal fears of children's outdoor play. *Family relations, 60*(4), 461-475. https://doi.org/https://doi.org/10.1111/j.1741-3729.2011.00660.x

Kmet, L. M., Lee, R. C., & Cook, L. S. (2004). *Standard quality assessment criteria for evaluating primary research papers from a variety of fields: Alberta Heritage Foundation for Medical Research*. Alberta Heritage Foundation for Medical Research (AHFMR.

Knox, S. (1997). Development and current use of the Knox Preschool Play Scale. In L. D. F. Parham, L.S. (Ed.), *Play in occupational therapy for children* (pp. 35-51). Mosby.

Kossyvaki, L., & Papoudi, D. (2016). A Review of Play Interventions for Children with Autism at School. *International Journal of Disability, Development and Education, 63*(1), 45-63. https://doi.org/10.1080/1034912x.2015.1111303

Kuhaneck, H., Spitzer, S. L., & Bodison, S. C. (2020). A Systematic Review of Interventions to Improve the Occupation of Play in Children With Autism. *OTJR: Occupation, Participation and Health, 40*(2), 83-98.

Kuhaneck, H. M., & Watling, R. (2015). Occupational therapy: Meeting the needs of families of people with autism spectrum disorder. *American Journal of Occupational Therapy, 69*(5), 6905170010p6905170011-6905170010p6905170015.

Kuo, A. (2011). A transactional view: Occupation as a means to create experiences that matter. *Journal of Occupational Science, 18*(2), 131-138.

Kuonza, L. R., Tshuma, C. D., Shambira, G. N., & Tshimanga, M. (2010). Non-adherence to the single dose nevirapine regimen for the prevention of mother-to-child transmission of HIV in Bindura town, Zimbabwe: a cross-sectional analytic study. *BMC Public Health, 10*(1), 218.

Landau, R., Amiel-Laviad, R., Berger, A., Atzaba-Poria, N., & Auerbach, J. G. (2009, Apr). Parenting of 7-month-old infants at familial risk for ADHD during infant's free play, with restrictions on interaction. *Infant Behav Dev, 32*(2), 173-182. https://doi.org/10.1016/j.infbeh.2008.12.007

Leadley, S., & Hocking, C. (2017). An occupational perspective of childhood poverty. *New Zealand Journal of Occupational Therapy, 64*(1), 23.

Lee, S.-J., Li, L., & Thammawijaya, P. (2013). Parenting styles and emotional intelligence of HIV-affected children in Thailand. *AIDS care, 25*(12), 1536-1543.

Liberati, A., Altman, D. G., Tetzlaff, J., Mulrow, C., Gøtzsche, P. C., Ioannidis, J. P. A., Clarke, M., Devereaux, P. J., Kleijnen, J., & Moher, D. (2009). The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration. *PLoS medicine, 6*(7), e1000100.

Linn, M. I., Goodman, J. F., & Lender, W. L. (2000). Played Out? Passive Behavior by Children with Down Syndrome during Unstructured Play. *Journal of Early Intervention, 23*(4), 264-278. https://doi.org/10.1177/1053815100023004060

Lisy, K., & Porritt, K. (2016). Narrative synthesis: considerations and challenges. *JBI Evidence Implementation, 14*(4), 201.

Lynch, H., Hayes, N., & Ryan, S. (2016). Exploring socio-cultural influences on infant play occupations in Irish home environments. *Journal of occupational science, 23*(3), 352-369.

Lynch, H., & Moore, A. (2016). Play as an occupation in occupational therapy. *British Journal of Occupational Therapy, 79*(9), 519-520.

Lynch, H., Prellwitz, M., Schulze, C., & Moore, A. H. (2018). The state of play in children's occupational therapy: A comparison between Ireland, Sweden and Switzerland. *British Journal of Occupational Therapy, 81*(1), 42-50.

Malone, M. (2009). Patterns of home-and classroom-based toy play of preschoolers with and without intellectual disabilities. *International Journal of Disability, Development and Education, 56*(4), 333-347. https://doi.org/10.1080/10349120903306558

Manjengwa, J., Matema, C., & Tirivanhu, D. (2016). Understanding urban poverty in two high-density suburbs of Harare, Zimbabwe. *Development Southern Africa, 33*(1), 23-38.

Manjokoto, C., & Ranga, D. (2017). Opportunities and challenges faced by women involved in informal cross-border trade in the city of Mutare during a prolonged economic crisis in Zimbabwe. *Journal of the Indian Ocean Region, 13*(1), 25-39.

Masanjala, W. (2007). The poverty-HIV/AIDS nexus in Africa: a livelihood approach. *Social science & medicine, 64*(5), 1032-1041.

Mattson, G., & Kuo, D. Z. (2019). Psychosocial factors in children and youth with special health care needs and their families. *Pediatrics, 143*(1), 1-15. https://doi.org/https://doi.org/10.1542/peds.2018-3171

McIndoe-Calder, T., Bedi, T., & Mercado, R. (2019). Hyperinflation in Zimbabwe. In *Hyperinflation in Zimbabwe* (pp. 9-25). Springer.

McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P. W., Perrin, J. M., Shonkoff, J. P., & Strickland, B. (1998). A new definition of children with special health care needs. *Pediatrics, 102*(1), 137-139.

McPherson, S., Reese, C., & Wendler, M. C. (2018). Methodology update: Delphi studies. *Nursing research, 67*(5), 404-410.

Meissner, R. J. (2016). *A randomised control trial comparing occupational therapy interventions that aim to improve developmental outcomes for HIV9positive children (aged 6 months-5 years) on ART* University of Cape Town].

Meissner, R. J., Ferguson, J., Otto, C., Gretschel, P., & Ramugondo, E. (2017). A play-informed, caregiver-implemented, home-based intervention for HIV-positive children and their families living in low-income conditions in South Africa. *World Federation of Occupational Therapists Bulletin, 73*(2), 83-87.

Miller, E., & Kuhaneck, H. (2008). Children's perceptions of play experiences and play preferences: A qualitative study. *American Journal of Occupational Therapy, 62*(4), 407-415.

Miller Kuhaneck, H., Tanta, K. J., Coombs, A. K., & Pannone, H. (2013). A survey of pediatric occupational therapists' use of play. *Journal of Occupational Therapy, Schools, & Early Intervention, 6*(3), 213-227.

Miller, L. S., Wu, M., Schettine, A. M., & Cogan, L. W. (2018). Identifying children with special health care needs using medicaid data in New York state medicaid managed care. *Health services research, 53*(6), 4157-4177.

Milteer, R. M., & Ginsburg, K. R. (2012, Jan). The importance of play in promoting healthy child development and maintaining strong parent-child bond: focus on children in poverty. *Pediatrics, 129*(1), e204-213. https://doi.org/10.1542/peds.2011-2953

Milteer, R. M., Ginsburg, K. R., & Mulligan, D. A. (2012). The importance of play in promoting healthy child development and maintaining strong parent-child bond: Focus on children in poverty. *Pediatrics, 129*(1), e204-e213.

Mlambo, T., Jelsma, J., Rusakaniko, S., Dale, N., & Chingono, A. (2017). Predictors of Zimbabwean children's neuro-cognitive performance on the Detroit Tests of Learning Aptitude fourth edition (DTLA-4): Implications for policy, practice and research. *World Federation of Occupational Therapists Bulletin, 73*(2), 94-106.

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Annals of internal medicine, 151*(4), 264-269. https://watermark.silverchair.com/0000605-200908180-00008

Moore, A., & Lynch, H. (2018). Play and play occupation: a survey of paediatric occupational therapy practice in Ireland. *Irish Journal of Occupational Therapy*.

Munambah, N., Cordier, R., Chiwaridzo, M., & Ramugondo, E. L. (2020). Play profiles of children with HIV/Aids: A comparative study. *Australian Occupational Therapy Journal*.

Munambah, N., Cordier, R., Speyer, R., Toto, S., & Ramugondo, E. L. (2020, 2020/11/20). A Systematic Review Comparing the Play Profiles of Children with Special Health Care Needs with Typically Developing Children. *BioMed Research International, 2020*, 9582795. https://doi.org/10.1155/2020/9582795

Munambah, N., Gretschel, P., & Sonday, A. (2020). Being a mother of a child with HIV-related Neurodevelopmental Disorders in the Zimbabwean Context. *South African Journal of Occupational Therapy, 50*(1), 35-40.

Murchie, P., Hannaford, P. C., Wyke, S., Nicolson, M. C., & Campbell, N. C. (2007). Designing an integrated follow-up programme for people treated for cutaneous malignant melanoma: a practical application of the MRC framework for the design and evaluation of complex interventions to improve health. *Family practice, 24*(3), 283-292.

Nabors, L. (1995, 1995). Attitudes, friendship ratings, and behaviors for typically developing preschoolers interacting with peers with disabilities. biennial meeting of the Society for Research in Child Development, Indianapolis.

National Health and Medical Research Council. (2000). Guide to the Development, Implementation and Evaluation of Clinical Practice Guidelines. *Canberra: National Health and Medical Research Council, 88*.

Okimoto, A. M., Bundy, A., & Hanzlik, J. (2000). Playfulness in children with and without disability: Measurement and intervention. *American Journal of Occupational Therapy, 54*(1), 73-82. https://doi.org/10.5014/ajot.54.1.73

Otto, C. (2016). *The impact of play-informed caregiver-implemented home-based intervention on the academic learning outcomes for HIV positive children (aged 5 years to 8 years) on Antiretroviral Therapy (ART) living in low income conditions: a randomized control trial* University of Cape Town].

Parsons, L., Cordier, R., Munro, N., & Joosten, A. (2019). A Play-Based, Peer-Mediated Pragmatic Language Intervention for School-Aged Children on the Autism Spectrum: Predicting Who Benefits Most. *Journal of autism and developmental disorders, 49*(10), 4219-4231.

Parten, M. B. (1933). Social play among preschool children. *The Journal of Abnormal and Social Psychology, 28*(2), 136.

Pascoe, S. J. S., Langhaug, L. F., Mavhu, W., Hargreaves, J., Jaffar, S., Hayes, R., & Cowan, F. M. (2015). Poverty, food insufficiency and HIV infection and sexual behaviour among young rural Zimbabwean women. *PloS one*, *10*(1), e0115290.

Patton, M. Q. (1990). *Qualitative evaluation and research methods*. SAGE Publications, inc.

Pearton, J. L., Ramugondo, E., Cloete, L., & Cordier, R. (2014, Aug). Playfulness and prenatal alcohol exposure: a comparative study. *Aust Occup Ther J*, *61*(4), 259-267. https://doi.org/10.1111/1440-1630.12118

Pereira, R. B., & Whiteford, G. E. (2013). Understanding social inclusion as an international discourse: Implications for enabling participation. *British Journal of Occupational Therapy*, *76*(2), 112-115.

Potterton, J., Hilburn, N., & Strehlau, R. (2016). Developmental status of preschool children receiving cART: A descriptive cohort study. *Child: care, health and development*, *42*(3), 410-414.

Potterton, J., Stewart, A., Cooper, P., Goldberg, L., Gajdosik, C., & Baillieu, N. (2009). Neurodevelopmental delay in children infected with human immunodeficiency virus in Soweto, South Africa. *Vulnerable children and youth studies*, *4*(1), 48-57. https://doi.org/https://doi.org/10.1080/17450120802183728

Power, R., Langhaug, L. F., Nyamurera, T., Wilson, D., Bassett, M. T., & Cowan, F. M. (2004). Developing complex interventions for rigorous evaluation—a case study from rural Zimbabwe. *Health education research*, *19*(5), 570-575.

Prater, M. A., Carter, N., Hitchcock, C., & Dowrick, P. (2012). Video self-modeling to improve academic performance: A literature review. *Psychology in the Schools*, *49*(1), 71-81.

Ramugondo, E. (2004). Play and playfulness: Children living with HIV/AIDS. *Transformation through occupation*, 171-185.

Ramugondo, E. (2018). Healing work: intersections for decoloniality. *World Federation of Occupational Therapists Bulletin*, *74*(2), 83-91.

Ramugondo, E., Ferreira, A., Chung, D., & Cordier, R. (2018). A Feasibility RCT Evaluating a Play-Informed, Caregiver-Implemented, Home-Based Intervention to Improve the Play of Children Who Are HIV Positive. *Occup Ther Int*, *2018*, 3652529. https://doi.org/10.1155/2018/3652529

Ramugondo, E. L. (2005). Unlocking spirituality: Play as a health promoting occupation in the context of HIV/AIDS. *Occupational therapy without borders: Learning from the spirit of survivors. New York, NY: Elsevier/Churchill Livingstone*, 313-325.

Ramugondo, E. L. (2012). Intergenerational play within family: The case for occupational consciousness. *Journal of Occupational Science, 19*(4), 326-340.

Ramugondo, E. L. (2015). Occupational consciousness. *Journal of Occupational Science, 22*(4), 488-501.

Ramugondo, E. L., & Kronenberg, F. (2015). Explaining collective occupations from a human relations perspective: Bridging the individual-collective dichotomy. *Journal of Occupational Science, 22*(1), 3-16. https://doi.org/https://doi.org/10.1080/14427591.2013.781920

Rebeiro, K. L. (2001). Enabling occupation: The importance of an affirming environment. *Canadian Journal of Occupational Therapy, 68*(2), 80-89.

Reilly, M. (1974). *Play as exploratory learning: Studies of curiosity behavior*. Sage Publications, Inc.

Rigby, P., & Gaik, S. (2007). Stability of playfulness across environmental settings: A pilot study. *Physical & Occupational Therapy in Pediatrics, 27*(1), 27-43.

Rodger, S., Ashburner, J., Cartmill, L., & Bourke-Taylor, H. (2010). Helping children with autism spectrum disorders and their families: Are we losing our occupation-centred focus? *Australian Occupational Therapy Journal, 57*(4), 276-280.

Rodger, S., & Kennedy-Behr, A. (2019). Occupational therapy: current approaches: Current approaches. In *Understanding Motor Behaviour in Developmental Coordination Disorder* (pp. 159-172). Routledge.

Rodger, S., & Ziviani, J. (1999). Play-based occupational therapy. *International Journal of Disability, Development and Education, 46*(3), 337-365.

Sabzevari, S., & Nematollahi, M. (2016). The burden of care: mothers' experiences of children with congenital heart disease. *International journal of community based nursing and midwifery, 4*(4), 374.

Sacha Cordiano, T. J. R. S. W., & Short, E. J. (2008). Development and Validation of the Affect in Play Scale – Brief Rating Version (APS – BR). *Journal of Personality Assessment, 90*(1), 52-60. https://doi.org/10.1080/00223890701693744

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in nursing & health, 23*(4), 334-340.

Sannicandro, T., Parish, S. L., Son, E., & Powell, R. M. (2017). Health care changes for children with special health care needs, 2005–2011. *Maternal and child health journal, 21*(3), 524-530.

Schurgers, J., Sinyangwe, S., Burger, S., Van Nieuwkerk, J., & Kamanga, E. (2010). Giving Children with HIV and AIDS a Future; The need for occupational therapy of HIV-positive children with developmental delay. *Medical Journal of Zambia, 37*(2), 93-98.

Simaan, J. (2020). Decolonising occupational science education through learning activities based on a study from the Global South. *Journal of Occupational Science, 27*(3), 432-442.

Skaines, N., Rodger, S., & Bundy, A. (2006). Playfulness in children with autistic disorder and their typically developing peers. *British Journal of Occupational Therapy, 69*(11), 505-512.

Skard, G., & Bundy, A. C. (2008). Test of Playfulness. In *Play in occupational therapy for children* (pp. 71-93). https://doi.org/10.1016/b978-032302954-4.10004-2

Skeen, S., Sherr, L., Tomlinson, M., Croome, N., Ghandi, N., Roberts, J. K., & Macedo, A. (2017). Interventions to improve psychosocial well-being for children affected by HIV and AIDS: a systematic review. *Vulnerable Child Youth Stud, 12*(2), 91-116. https://doi.org/10.1080/17450128.2016.1276656

Skinner, M. L., Buysse, V., & Bailey, D. B. (2004). Effects of age and developmental status of partners on play of preschoolers with disabilities. *Journal of Early Intervention, 26*(3), 194-203.

Skivington, K., Matthews, L., Craig, P., Simpson, S., & Moore, L. (2018). Developing and evaluating complex interventions: updating Medical Research Council guidance to take account of new methodological and theoretical approaches. *The Lancet, 392*, S2.

Smyth, M. M., & Anderson, H. I. (2000). Coping with clumsiness in the school playground: Social and physical play in children with coordination impairments. *British Journal of Developmental Psychology, 18*(3), 389-413.

Snow, J., & Mann, M. (2013). Qualtrics survey software: handbook for research professionals. *Qualtrics Labs, Inc*.

Stagnitti, K. (2003). A review of play and play assessment used in occupational therapy. *Journal of Japanese association of occupational therapists, 22*(3), 267-280.

Stagnitti, K., Bailey, A., Hudspeth Stevenson, E., Reynolds, E., & Kidd, E. (2016). An investigation into the effect of play-based instruction on the development of play skills and oral language. *Journal of Early Childhood Research, 14*(4), 389-406.

Stagnitti, K., O'Connor, C., & Sheppard, L. (2012). Impact of the learn to play program on play, social competence and language for children aged 5–8 years who attend a specialist school. *Australian Occupational Therapy Journal, 59*(4), 302-311.

Steinert, J. I., Cluver, L., Melendez-Torres, G. J., & Herrero Romero, R. (2017). Relationships between poverty and AIDS Illness in South Africa: an investigation of urban and rural households in KwaZulu-Natal. *Global public health, 12*(9), 1183-1199.

Sterman, J., Naughton, G., Froude, E., Villeneuve, M., Beetham, K., Wyver, S., & Bundy, A. (2016). Outdoor play decisions by caregivers of children with disabilities: A systematic review of qualitative studies. *Journal of Developmental and Physical Disabilities, 28*(6), 931-957.

Sumsion, T. (1998). The Delphi technique: an adaptive research tool. *British Journal of Occupational Therapy, 61*(4), 153-156.

Therapists, W. F. o. O. (2006). *Position statement on human rights* http://www.wfot.org/office_files/Human%20Rights%20Position%20Statement%20Final.pdf

Todd, B. K., Fischer, R. A., Di Costa, S., Roestorf, A., Harbour, K., Hardiman, P., & Barry, J. A. (2018). Sex differences in children's toy preferences: A systematic review, meta-regression, and meta-analysis. *Infant and Child Development, 27*(2), e2064.

Townsend, E., & Wilcock, A. (2004). Occupationaljustice and client-centred practice: a dialogue in progress. *Canadian journal of occupational therapy, 71*(2), 75-87.

UNICEF. (1989). *Convention on the Rights of the Child*.

UNICEF. (2010). *National Child Survival Strategy for Zimbabwe, 2010-2015 URL: https://www. unicef. org/zimbabwe* (Young_Child_Survival_Doc-Complete. pdf [accessed 2018-05-08][WebCite Cache ID 6zGBgDoka], Issue.

Uren, N., & Stagnitti, K. (2009). Pretend play, social competence and involvement in children aged 5–7 years: The concurrent validity of the Child-Initiated Pretend Play Assessment. *Australian occupational therapy journal, 56*(1), 33-40.

Uys, A. (2016). *A randomized control trial investigating the effects of a play-informed care-giver implemented home-based intervention on playfulness for HIV positive children aged 10 months to 8 years on HAART from a low socio-economic status* University of Cape Town].

Van Der Lee, J. H., Mokkink, L. B., Grootenhuis, M. A., Heymans, H. S., & Offringa, M. (2007). Definitions and measurement of chronic health conditions in childhood: a systematic review. *JAMA, 297*(24), 2741-2751.

Van Dyck, P. C., Kogan, M. D., McPherson, M. G., Weissman, G. R., & Newacheck, P. W. (2004). Prevalence and characteristics of children with special health care needs. *Archives of pediatrics & adolescent medicine, 158*(9), 884-890.

Vandenberg, B., & Kielhofner, G. (1982). Play in evolution, culture, and individual adaptation: Implications for therapy. *American Journal of Occupational Therapy, 36*(1), 20-28.

Venkatesan, S. (2014). Availability of toys for children with developmental disabilities. *Journal of Disability Management and Special Education, 4*(1), 58-70.

Venkatesan, S., & Ravindran, N. (2012a). Play behaviors and activities in siblings of children with developmental disabilities. *Journal of Indian Academy of Applied Psychology, 38*(1), 74-83.

Venkatesan, S., & Ravindran, N. (2012b). Play behaviours and activities of siblings of children with developmental disabilities. *Journal of the Indian Academy of Applied Psychology, 38*(1), 74-83.

Watts, T., Stagnitti, K., & Brown, T. (2014). Relationship between play and sensory processing: A systematic review. *American Journal of Occupational Therapy, 68*(2), e37-e46.

Whiteford, G. (2000). Occupational deprivation: Global challenge in the new millennium. *British journal of occupational therapy, 63*(5), 200-204. https://doi.org/https://doi.org/10.1177/030802260006300503

Whitehead, N., Potterton, J., & Coovadia, A. (2014). The neurodevelopment of HIV-infected infants on HAART compared to HIV-exposed but uninfected infants. *AIDS care, 26*(4), 497-504.

Wijlaars, L. P. M. M., Gilbert, R., & Hardelid, P. (2016). Chronic conditions in children and young people: learning from administrative data. *Archives of Disease in Childhood, 101*(10), 881-885. https://doi.org/10.1136/archdischild-2016-310716

Wilcock, A. A. (2006). *An occupational perspective of health*. Slack Incorporated.

Wilcock, A. A. (2007). Occupation and health: Are they one and the same? *Journal of Occupational Science, 14*(1), 3-8. https://doi.org/https://doi.org/10.1080/14427591.2007.9686577

Wilding, C. (2011). Raising awareness of hegemony in occupational therapy: The value of action research for improving practice. *Australian occupational therapy journal, 58*(4), 293-299.

Wilkes-Gillan, S., Bundy, A. C., Cordier, R., Lincoln, M., & Chen, Y.-W. (2016). A randomised controlled trial of a play-based intervention to improve the social play skills of children with attention deficit hyperactivity disorder (ADHD). *PLOS one, 11*(8), e0160558. https://doi.org/10.1371/journal.pone.0160558

Wilkes-Gillan, S., Cantrill, A., Cordier, R., Barnes, G., Hancock, N., & Bundy, A. (2017). The use of video-modelling as a method for improving the social play skills of children with attention deficit hyperactivity disorder (ADHD) and their playmates. *British Journal of Occupational Therapy, 80*(4), 196-207. https://doi.org/10.1177/0308022617692819

Wilkes-Gillan, S., Bundy, A., Cordier, R., & Lincoln, M. (2014). Eighteen-month follow-up of a play-based intervention to improve the social play skills of children with attention deficit hyperactivity disorder. *Australian occupational therapy journal, 61*(5), 299-307.

Wilkes, S., Cordier, R., Bundy, A., Docking, K., & Munro, N. (2011). A play-based intervention for children with ADHD: A pilot study. *Australian occupational therapy journal, 58*(4), 231-240.

7 LIST OF APPENDIXES

7.1 APPENDIX A: Theoretical Framework: Model of Children's Play

A descriptive model on children's play by Cooper (2000) provides a way of conceptualising the underlying skills and behavioural elements characteristic of play and the influence of both the individual and environmental factors on play. Figure 1 below presents a model of children's play.

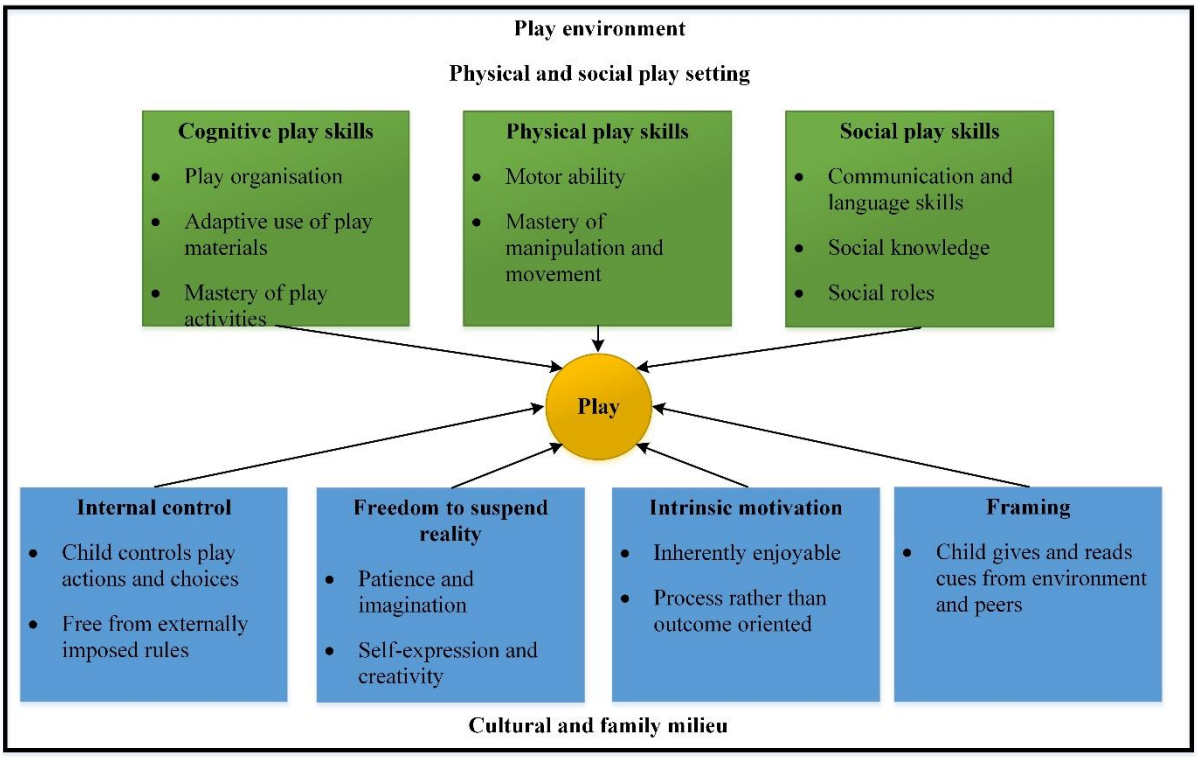


Figure 7.1: Model of children's play (adapted from Cooper, 2000)

The predicted impact of HIV/Aids on children's play

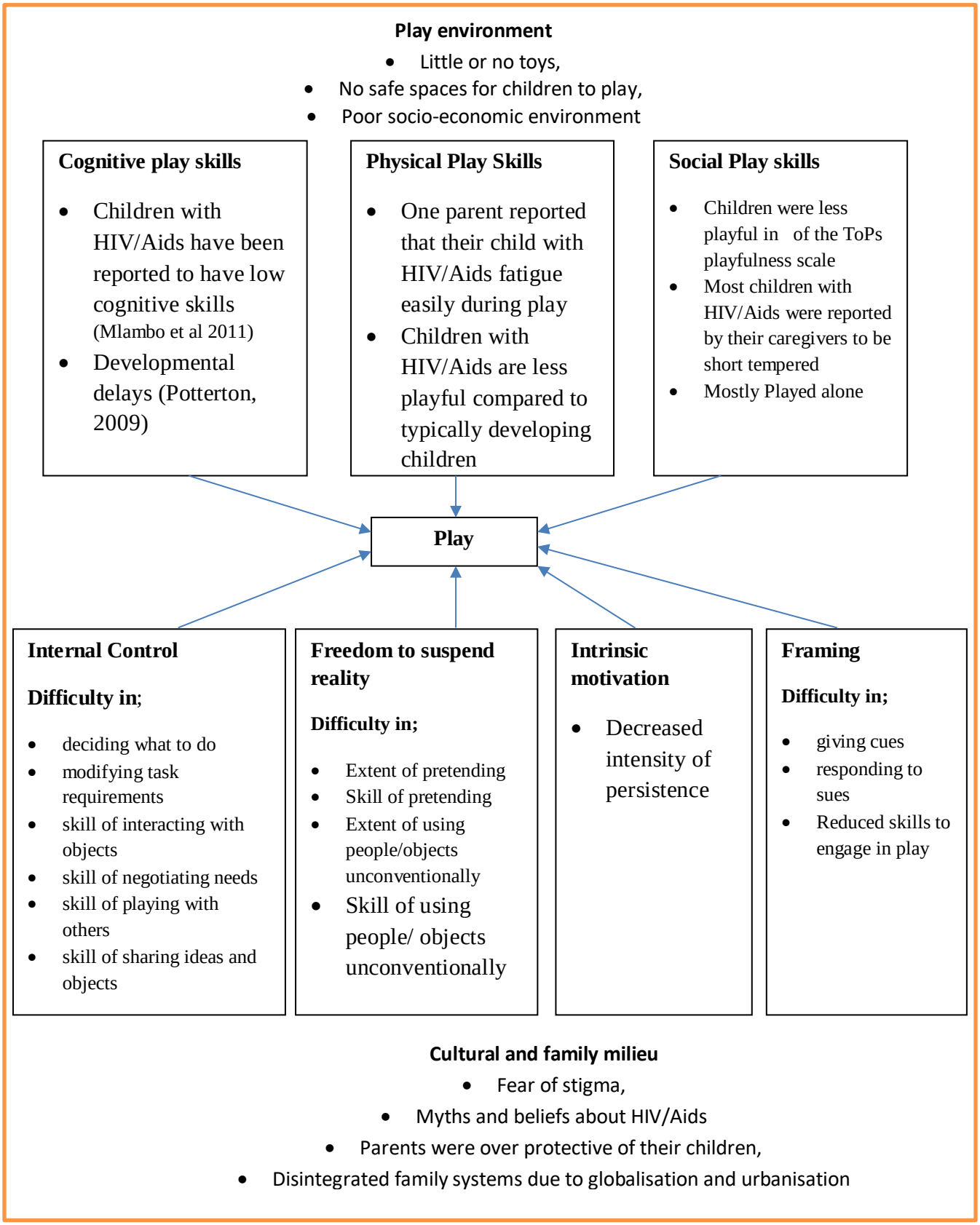


Figure 7.2: Predicted impact of HIV/Aids on children's play

The impact of HIV/Aids on children's play

Child's contribution to play

Engagement and participation in play depends largely on the on the child's cognitive, motor language and social skills development (Cooper 2000). Children infected with HIV/Aids are likely to have developmental delays and disabilities which pose a risk to play. A study by Potterton (2009) highlighted some of the common developmental disabilities in children with HIV/Aids as developmental delays, communication difficulties and physical disabilities. Prior to this Delphi study, the researchers used a test of playfulness to compare the level of playfulness of children with HIV/Aids against typically developing children. The study involved observing each child playing with a playmate for 15minutes indoors and then outdoors. The researchers also held in depth interviews with purposively selected caregivers of children with HIV/Aids to explore the barriers and facilitators to play. Findings from these research studies as well as a review of literature have informed this Delphi study.

Physical Skills and cognitive skills: Through this prior study, it was noted that children with HIV/Aids are likely to fatigue easily, hence will have difficulty in engaging in prolonged physical play. Generally, children with HIV/Aids were less playful as compared to typically developing children. A study by Mlambo (2015) also revealed that children with HIV/Aids are also likely to develop neurocognitive impairments which affect their engagement in play and school activities. Children with cognitive difficulties engage more in repetitive exploratory or stereotyped play and they lack skill to modify task or the environment during play (Cooper 2000).

Social Skills: Caregivers involved in our study reported that children with HIV/Aids are short tempered. Often these children would end up playing alone. The situation is also worsened by the fact that some of the children with HIV/Aids had communication difficulties, hence could not interact well with their peers. Findings from the Test of Playfulness indicated that children with HIV/Aids scored less as compared to typically developing children on skill of negotiating needs, sharing objects and playing with others.

Impact of HIV/Aids on elements of Playfulness

The construct of playfulness comprises of four elements namely; the elements of play include internal control, Freedom to suspend reality, intrinsic motivation and framing. These elements occur on a continuum and, when viewed in context, identify a child's playfulness profile (Pearton 2014).

Internal control refers to the child's ability to determine what happens and how or with whom she or he is playing with (Bundy, 1997). Using the test of playfulness, children with HIV/Aids performed significantly lower than typically developing children on six out of the twelve items on internal control. Due to the stigma and other social factors that come with HIV/Aids, children with HIV/Aids may have difficulty in initiating play or control their impulses in play.

Freedom to suspend reality refers to the child's ability to introduce non literal, pretend elements into play (Bundy, 1997). The decreased pretence and symbolic content has been described by caregivers involved in our study. Using the test of playfulness, children with

HIV/Aids performed significantly lower than typically developing children on six out of the twelve items on internal control.

Intrinsic motivation refers to a child's willingness to engage in play activities or with playmates(Cooper, 2000)**.** Children with HIV/Aids involved in our study were hesitant to start play or to change the course of play. Using the test of playfulness, children with HIV/Aids were not intensively persisting during play as compared to typically developing children.

Framing refers to the ability to appropriately give and read play cues from the environment and other playmates (Pearton et al., 2014). Using the test of playfulness, children with HIV/Aids performed significantly lower than typically developing children on extent of giving cues, skill of giving cues, responding to Cues and Skill of being engaged.

Impact of the environment on Child's play

Research has shown that HIV/Aids and poverty are interrelated and most people living with HIV/Aids live in low resourced settings. In our study, most of the participants were living in poverty and their daily occupations were centred on surviving from one day to the next. Thus, play was not a priority for the caregivers and most of the children did not have toys. Apart from the school playgrounds, there were no formally designated play spaces for the children to play. Caregivers reported that there are no safe play spaces for children to play. Feeling safe is a pre-requisite for a child to play (Cooper, 2000).

Due to the fear of stigma, caregivers tend to overprotect their children (Munambah, Gretschel and Sonday, 2020), hence controlling whom the child plays with, time of play and place of play. Overprotection has been linked with anxiety and other behavioural problems in children.

Conclusion

The model by Cooper (2000) has been used to understand the impact of HIV/Aids on children's play. The model highlights the need to develop play-based intervention to promote play in children with HIV/Aids.

7.2 APPENDIX B: Confirmation of Authorship

Confirmations by co-authors for inclusion of the following published articles in a PhD thesis by Nyaradzai Munambah (DNGNYA002)

Article	Publication Status	Journal	Co-Author Signature	Co-Author Signature	Co-Author Signature	Co-Author Signature
A Systematic Review Comparing the Play Profiles of Children with Special Health Care Needs with Typically Developing Children.	Published	BioMed Research International	Reinie Cordier	Elelwani Ramugondo	Renee Speyer	Sivuyisiwe Toto
Play profiles of children with HIV/Aids: A comparative study.	Published	Australian Occupational Therapy Journal	Reinie Cordier	Elelwani Ramugondo	Matthew Chiwaridzo	
Play of children living with HIV/Aids in a low resourced setting: Perspectives of caregivers	Under Review	British Journal of Occupational Therapy	Reinie Cordier	Elelwani Ramugondo		
A play-based intervention framework for promoting play of children with HIV/Aids in a low-resourced setting: Delphi Study	Under Review	Scandinavian Journal of Occupational Therapy	Reinie Cordier	Elelwani Ramugondo		

Signatures Removed

7.3 APPENDIX C: HREC latest renewal

UNIVERSITY OF CAPE TOWN

FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee

FHS016: Annual Progress Report / Renewal

HREC office use only (FWA00001637; IRB00001938)			
This serves as notification of annual approval, including any documentation described below.			
☒ Approved	Annual progress report	Approved until/next renewal date	30/05/21
☐ Not approved	See attached comments		
Signature Chairperson of the HREC/ Designee	Signature Removed	Date Signed	8/6/2020

Note: Please note that incomplete submissions will not be reviewed.
Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za.
Please clarify your plan for research-related activities during COVID-19 lockdown

Comments to PI from the HREC
I can confirm that the study is in its final phase of data collection, which does not involve any contact with human subjects. This involves an online Delphi study with 50 participants who are professionals and are experts in either play or HIV/Aids. The first two phases of data collection were completed in 2019. Sincere apologies for not submitting this renewal form before the date of the previous approval lapsed. Both the student and I are aware that this should not have been allowed to occur.

Principal Investigator to complete the following:

1. Protocol information

Date (when submitting this form)	05 June 2020		
HREC REF Number	640/2017	Current Ethics Approval was granted until	30 May 2020
Protocol title	Comparing the differences and similarities of play profiles and play environments for children with and without specified chronic illness living in a low resourced setting of Zimbabwe		
Protocol number (if applicable)			
Are there any sub-studies linked to this study?	☐ Yes √☐ No		
If yes, could you please provide the HREC Ref's for all sub-studies? **Note:** A separate FHS016 must be submitted for each sub-study.			

HUMAN RESEARCH ETHICS COMMITTEE
08 JUN 2020
HEALTH SCIENCES FACULTY
UNIVERSITY OF CAPE TOWN

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

7.4 APPENDIX D: HREC Approval letter

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: sumayah.ariefdien@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

07 May 2018

HREC REF: 640/2017

Prof E Ramugondo
Department of Health & Rehab Sciences
Occupational Therapy
F-45, OMB

Dear Prof Ramugondo

PROJECT TITLE: COMPARING THE DIFFERENCES AND SIMILARITIES OF PLAY PROFILES AND PLAY ENVIRONMENTS IN CHILDREN WITH AND WITHOUT SPECIFIED CHRONIC ILLNESS LIVING IN A LOW RESOURCED SETTING OF ZIMBABWE (PHD CANDIDATE - N MUNAMBAH)

Thank you for your response letter dated 19 March 2018, addressing the issues raised by the Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30 May 2019.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

We acknowledge that the student: N Munambah will also be involved in this study.

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval before the research may occur.
Yours sincerely

Signature Removed

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

7.5 APPENDIX E: Approval to use playroom for data collection

DEPARTMENT OF REHABILITATION

HARARE, Zimbabwe

Telephone:263-4-791631 Ext 2175/6
Fax:263-4-797800/724912/335249/791995
Telex: 26580 UNIVZ ZW
Telegrams: UNIVERSITY
E-mail:rehab@medsch.uz.ac.zw

COLLEGE OF HEALTH SCIENCES **UNIVERSITY OF ZIMBABWE**

17 May 2018

Dear Mrs N. Munambah

RE: REQUEST FOR PERMISSION TO USE THE PLAYROOM TO CONDUCT A STUDY

Firstly I would like to congratulate you for choosing a research area that will contribute to the growth of paediatric occupational therapy services in Zimbabwe.

Permission has been granted to use the playroom for conducting your study. Please liaise with the senior technician in the department to make sure the room is adequately prepared for use during the study period.

I wish you all the best with your research.

Yours sincerely

Signature Removed

MS T.M CHIKWANHA

OFFICIAL
UNIVERSITY OF ZIMBABWE
COLLEGE OF HEALTH SCIENCE
REHABILITATION DEPARTMENT
P.O.BOX A178, AVONDALE
HARARE, ZIMBABWE

7.6 APPENDIX F: Approval to recruit participants from Harare Hospital

elephone: 621100-19
ax: 621157

ZIMBABWE

Reference: HCHEC 310618/55

HARARE CENTRAL HOSPITAL
P. O. Box ST 14
SOUTHERTON
Harare

02 July 2018

Ms. Nyaradzai Munambah
University of Zimbabwe
College of Health Sciences
Department of Rehabilitation
Private Bag A198, Avondale
HARARE

Dear Ms. Munambah,

REF: COMPARING THE DIFFERENCES AND SIMILARITIES OF PLAY PROFILES AND PLAY ENVIRONMENTS FOR CHILDREN WITH AND WITHOUT SPECIFIED CHRONIC ILLNESS LIVING IN A LOW RESOURCED SETTING OF ZIMBABWE

I am glad to advise you that your application to conduct a quality improvement project entitled: **Comparing the Differences and Similarities of Play Profiles and Play Environments for Children with and Without Specified Chronic Illness Living in a Low Resourced Setting of Zimbabwe (Ref: HCHEC 310518/55),** has been Approved by the Harare Hospital Ethics Committee.

This approval is premised on the submitted protocol. Should you decide to vary your protocol in any material way please submit these for further approval.

You are advised to avail the results of your project whether positive or negative to the hospital through the committee for our information.

Yours sincerely.

HARARE CENTRAL HOSPITAL
DEPARTMENT OF MEDICINE
02 JUL 2018
P. O. BOX ST14, SOUTHERTON
HARARE, ZIMBABWE

Signature Removed

DR. C. Pasi
Chairman Harare Central Hospital Ethics Committee

7.7 APPENDIX G: Approval from institutional review board (JREC)

Parirenyatwa Group of Hospitals

Joint Research Ethics Committee For The University of Zimbabwe, College of Health Sciences and Parirenyatwa Group of Hospitals

JREC Office No. 4, 5th Floor College of Health Sciences Building
Telephone: +263 4 708140/ 791631 Exts 2241/2242
Email:jrec.office@gmail.com/jrec@medsch.uz.ac.zw, website:www.jrec.uz.ac.zw

University of Zimbabwe College of Health Sciences

APPROVAL LETTER

Date: 20 July 2018 **JREC Ref:** 163/18

Names of Researcher: Nyaradzai Munambah
Address: University of Zimbabwe, Department of Rehabilitation.

RE: COMPARING THE DIFFERENCES AND SIMILARITIES OF PLAY PROFILES AND PLAY ENVIRONMENTS FOR CHILDREN WITH AND WITHOUT SPECIFIED CHRONIC ILLNESS LIVING IN A LOW RESOURCED SETTING OF ZIMBABWE.

Thank you for your application for ethical review of the above mentioned research to the Joint Research Ethics Committee. Please be advised that the Joint Research Ethics Committee has reviewed and approved your application to conduct the above named study. You are still required to obtain MRCZ and RCZ approval before you commence the study if required by the nature of your study.

- APPROVAL NUMBER: JREC/163/18
- APPROVAL DATE: 20 July 2018
- EXPIRY DATE: 19 July 2019

This approval is based on the review and approval of the following documents that were submitted to the Joint Ethics Committee:

a) Completed Application Form
b) Full Study Protocol
c) Informed Consent in English and/or appropriate local language

After this date the study may only continue upon renewal. For purposes of renewal please submit a completed renewal form (obtainable from the JREC office) and the following documents before the expiry date:

a. Progress report
b. A Summary of adverse events
c. A DSMB report

OHRP IRB Number: IORG 00008914
PARIRENYATWA GROUP OF HOSPITALS FWA- 00010360

7.8 APPENDIX H: Approval from institutional review board (MRCZ)

Telephone: 791792/791193
Telefax: (263) - 4 - 790715
E-mail: mrcz@mrcz.org.zw
Website: http://www.mrcz.org.zw

Medical Research Council of Zimbabwe
Josiah Tongogara / Mazoe Street
P. O. Box CY 573
Causeway
Harare

APPROVAL

MRCZ/A/2371 **10 December, 2018**

Nyaradzai Munambah
UZCHS-REHABILITATION DEPARTMENT
P O Box A178
Avondale
Harare

RE:-International surveillance study of movement of behaviors in the early years (4 years old)(SUNRISE) Pilot Study: Zimbabwe

Thank you for the application for review of Research Activity that you submitted to the Medical Research Council of Zimbabwe (MRCZ). Please be advised that the Medical Research Council of Zimbabwe has **reviewed** and **approved** your application to conduct the above titled study.

This approval is based on the review and approval of the following documents that were submitted to MRCZ for review:-

1. Completed MRCZ 101 application form
2. Protocol version 3.0 dated 23 November 2018
3. Informed consent forms(English and Shona) version 3.0 dated 23 November 2018
4. Data collection tools

- **APPROVAL NUMBER** **: MRCZ/A/2371**
  This number should be used on all correspondence, consent forms and documents as appropriate.
- **TYPE OF MEETING** **: Expedited**
- **APPROVAL DATE** **: 10 December 2018**
- **EXPIRATION DATE** **: 09 December 2019**

After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the MRCZ Offices should be submitted three months before the expiration date for continuing review.

•**SERIOUS ADVERSE EVENT REPORTING**: All serious problems having to do with subject safety must be reported to the Institutional Ethical Review Committee (IERC) as well as the MRCZ within 3 working days using standard forms obtainable from the MRCZ Offices or website.

•**MODIFICATIONS**: Prior MRCZ and IERC approval using standard forms obtainable from the MRCZ Offices is required before implementing any changes in the Protocol (including changes in the consent documents).

•**TERMINATION OF STUDY**: On termination of a study, a report has to be submitted to the MRCZ using standard forms obtainable from the MRCZ Offices or website.

•**QUESTIONS**: Please contact the MRCZ on Telephone No. (0242) 791792, 791193 or by e-mail on mrcz@mrcz.org.zw

Other

- Please be reminded to send in copies of your research results for our records as well as for Health Research Database.
- You're also encouraged to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study.

Yours Faithfully

Signature Removed

MRCZ SECRETARIAT
FOR CHAIRPERSON
MEDICAL RESEARCH COUNCIL OF ZIMBABWE

MEDICAL RESEARCH COUNCIL OF ZIMBABWE
2018 -12- 10
APPROVED
P.O. BOX CY 573 CAUSEWAY HARARE

PROMOTING THE ETHICAL CONDUCT OF HEALTH RESEARCH

7.9 APPENDIX I: Approval from Ministry of Primary and secondary schools

All communications should be addressed to "The Secretary for Primary and Secondary Education
Telephone: 732006
Telegraphic address : "EDUCATION"
Fax: 794505

ZIMBABWE

Reference: C/426/3 Hre
Ministry of Primary and Secondary Education
P.O Box CY 121
Causeway
HARARE

7 February 2019

Munambah Nyaradzai
University of Cape Town, Faculty of Health Sciences
Department of Occupational Therapy
Old Main Building, F56 Rm 73, Groote Schuur Hospital
7925 Observatory, Cape Town

Re: **PERMISSION TO CARRY OUT DOCTORAL RESEARCH IN HARARE PROVINCE: MBARE – HATFIELD, NORTHERN PARK, WAREEN PARK-MALBEREIGN, AND GLENVIEW MUFAKOSE DISTRICT.EYECOURT, AVONDALE, BLACKSTONE, GLENVIEW 9 AND DZIVARASEKWA 2 PRIMARY SCHOOLS**

Reference is made to your application to carry out research at the above mentioned schools in Harare Province on the research title:

"COMPARING THE DIFFERENCE AND SIMILARITIES OF PLAY PROFILES AND ENVIRONMENTS FOR CHILDREN WITH AND WITHOUT SPECIFIED CHRONIC ILLNESS LIVING IN A LOW RESOURCED SETTING IN ZIMBABWE."

Permission is hereby granted. However, you are required to liaise with the Provincial Education Director Harare Province, who is responsible for the schools which you want to involve in your research. You should ensure that your research work does not disrupt the normal operations of the schools. Where students are involved, parental consent is required.

You are also required to provide a copy of your final report to the Secretary for Primary and Secondary Education.

POLICY PLANNING RESEARCH
22 FEB 2019

T Thabela (Mrs)
SECRETARY FOR PRIMARY AND SECONDARY EDUCATION
cc: PED – Harare Province

THE HEAD
GLEN VIEW NO. 9 COUNCIL PRY. SCHOOL
GLEN VIEW/MUFAKOSE DISTRICT, HRE
04 MAR 2019
P.O. BOX GV 100, GLEN VIEW
PHONE 690080
Email glenviewnine@gmail.com

Ministry Of Primary And Secondary Education
Glen View / Mufakose District
04 MAR 2019
INSPECTOR
P.O. Box GV 63 Glen View, Harare

Signature Removed

7.10 APPENDIX J: Information letter to caregivers (English)

School of Health and Rehabilitation Sciences

Faculty of Health Sciences

Divisions of Communications Sciences and Disorders, Nursing and Midwifery, Occupational Therapy, Physiotherapy

F45 Old Main Building, Groote Schuur Hospital,

Observatory 7925

Dear Participant

Study Title: Comparing the differences and similarities of play profiles and play environments for children with and without specified chronic illness living in a low resourced setting of Zimbabwe.

Introduction

My name is Nyaradzai Munambah and I am a postgraduate student (PhD) in the department of Occupational therapy at the University of Cape Town, South Africa. I am doing a study in Zimbabwe, on how play for children with chronic illness is similar or different to that of typically growing children living in a low resourced setting.' The study was approved by University of Cape Town, Faculty of Health Sciences Human Research Ethics Committee (HREC ref no. 640/2017) and in Zimbabwe the Medical Research Council of Zimbabwe (MRCZ ref no. A/2364) and the Joint Research and Ethics Committee (JREC ref no.163/18). Also permission was sought from Parirenyatwa Group of Hospitals, Harare central Hospital and participating preschools. I am inviting you to take part in this study.

Purpose of Study

The purpose of this study is to get an understanding of play in children with chronic illness (such as HIV/AIDS and Cancer) with the aim of developing ways to facilitate and promote play in these children. The information and knowledge produced through the study will be included in occupational therapy professional practice in Zimbabwe for children with chronic illness.

Participant Selection

You are being invited to take part in this research because we feel that both you and your child can contribute much to our understanding of play in children with chronic illness.

Procedures involved in the study

Participation in this study is on voluntary basis, thus, upon accepting to participate in the study, you will be asked to sign an informed consent form. The study involves observing your child playing with a mate (a person who can be his/her sibling or friend that whom s/he is familiar with and often play together). You as the caregiver, will be involved in the selection of the playmate for your child. None of the children involved in this study should experience difficulty in performing two or more of the five items in the section: 'getting around' of WHODAS questionnaire. Your child will also undergo a health assessment by a qualified nurse to see he/she can take part in this study. Apart from the observations of the children playing, an interview will be done with you the caregiver, to collect information on details as well as how the child participants in play. The interview can be done either at your home, the hospital or any convenient place that you feel comfortable with. A date and time convenient to you will be set for the first play session of the children, at the play room in the department of Rehabilitation at the University of Zimbabwe. Two play sessions will be carried out in this study and each session is likely to take 30 minutes. The information recorded will not be shared with anyone, and no one else except the researcher will have access to the information documented during your interview. The entire play session will be video recorded, but no-one will be identified by

name on the tape. And information recorded will be safely kept in a secure office that is always locked. The videos will only be used for the purposes of this research only and will be destroyed at the end of the study.

Risks and Discomforts
In this study, the researcher will ask your child and his/her playmate to play and be recorded. In the event that the play of the children is dangerous the recording will be stopped and appropriate interventions will be sort immediately. If you or the researcher feels that you need counselling and psychosocial support services, a referral will be made to Parirenyatwa Hospital. An arrangement for such services will be made prior to the beginning of the study.

Benefits and/ Compensation
Participation in this study is on voluntary basis. There is no direct remuneration for taking part in this study, but participants will be given transport money of $5. Each of the children who participate in the study will be given a toy of their choice from the playroom. Your participation is however likely to help in developing an understanding of play profiles and play environments of children with chronic illness. Refreshments will be served at the end of each session.

Voluntary Participation
If you feel you do not want to participate in this study for any reason you are free to do so. The normal treatment and services that you would need will not be affected in any way. You may stop participating in the research at any time that you wish and you will not be forced to give an explanation.

Confidentiality
The researcher and the research assistants will not be sharing information about you to anyone outside of the research team. The information that we collect from this research project will be kept private. Any information about yourself that you provide will have a number on it instead of your name. Only the researchers will know what your number is and will keep this information in a secure location.

Contact Details
If you have any questions, you can ask them now or later. If you wish to ask questions later, you may contact me, The Researcher:

Nyaradzai Munambah,
Cell phone Number: +263 775 428 950
Address: University of Zimbabwe,
College of health Sciences
Department of Rehabilitation
Private Bag A198
Avondale, Harare

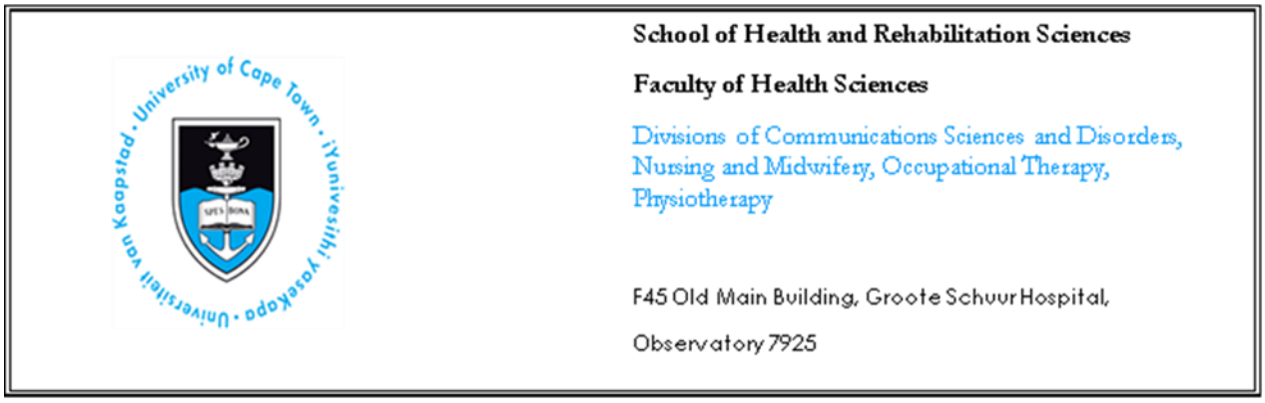
You can also contact, my supervisor at the university using the details below:
Elelwani Ramugondo telephone number +27 (0)21 650 2104, University of Cape Town.

If you have concerns about human rights and welfare of the research participants, Please contact the Chairperson of the UCT Faculty of Health Sciences Human Research Ethics Committee (HREC) is Professor Marc Blockman - telephone number +27 (0)21 406 6496 at University of Cape Town.

If you have concerns about human rights and welfare of the research participants, Please Contact the Medical Research Council of Zimbabwe on +263 784 956 128. Or to visit their offices at Corner Josiah Tongogara/ Mazowe Street, Harare, Zimbabwe.

7.11 APPENDIX K: Information letter to caregivers (Shona)

Tsamba ine zvinodakuzivikanwa nevachengeti



Anodikanwa arimutsvakurudzi

Musoro Wetsvakurudzo: Comparing the differences and similarities of play profiles and play environments for children with and without specified chronic illness living in a low resourced setting in Zimbabwe.

Nhanganyaya

Zita rangu ndiNyaradzai Munamba, ndiri mudzidzi we dzidzo yepamusorosoro (PHD) mudhipatimendi re Occupational therapy kuUniversity ye Capetown kuSouth Africa. Ndirikuita tsvakurudzo muZimbabwe, pamosoro pematambiro evana vane chirwere kwenguva refu kufanana kana kusiyana nemakuriro evana. Tsvakurudzo yakapihwa mvumo neUniversity of Cape Town, bazi re Health Sciences Human Research Ethics (HREC ref no.640/2017) ne Medical Research Council ye Zimbabwe (MRCZ ref no A/2364) ne Joint Research Ethics committee (JREC ref no164/18)

Mvumo yakakumbirwa yakapihwa zvakare kubva kuzvikwata zve Zvipatara zveParirenyatwa, chipatara chikuru che Harare ne zvikoro zvekutamba zvevana vadiki zvirikupindawo mutsvakurudzo.

Chinangwa Chetsvakurudzo

Chinangwa chetsvakurudzo ino ndeche kuwana kunzwisisa kwematambiro evana vane chirwere kwenguva refu (kufanana ne HIV/AIDS na Gomarara) nechinangwa chekuwana nzira dzekubatsiridza nekusimudzira matambiro muvana ava.

Ruzivo rwuchaburitswa kuburikidza ne tsvakurudzo rwuchasanganiswa mu occupational therapy professional practice mu Zimbabwe kuitira vana vane chirwere chenguva refu.

Kusarudzwa kwevachapinda mutsvakurudzo

Murikukokwa kupinda mutsvakurudzo ino nekuti tinofungidzira kuti mese imi nemwana wenyu munogona kubatsira zvakanyanya pakunzwisisa kwedu kwematambiro evana vana chirwere kwenguva refu.

Zvichaitwa Mutsvakurudzo

Kupinda kwenyu mutsvakurudzo kuzvipira, pamusoro pekubvuma kwenyu kupinda mutsvakurudzo, munozokumbirwa kusaina gwaro retenderano. Tsvakurudzo inosanganisira kutarisisa mwana wenyu achitamba nemumwe wake (munhu anogona kunge ari mwana anoberekwa pamwechete naye kana shamwari yakajairana naye yaananowanzo tamba nayo). Imi semuchengeti, muchava mumwe weavo vachasarudza mwana wekutamba nemwana wenyu. Hakuna mumwe wevana vari mutsvakurudzo ino vanofanirwa kunetseka nekuita zviviri kana kupfuura pane zvinhu zvishanu muchikamu.

Kunze kwekutarisisa kwe vana vachitamba,tichaita nguva yekukubvunzai semuchengeti, kuti tiwane ruzivo rwakadzama pamwechete nematambiro emwana nevamwe.

Kubvunza mibvunzo kunokwanisa kuitirwa kumba kwenyu, kuchipatara kana nzvimbo ipi zvayo yakafanira yamakasununguka nayo. Zuva nenguva yamakasununguka zvicharongwa kuita nguva yekutamba kwevana yekutanga, munzvimbo yekutambira mu dipatimendi re Rehabilitation kuUniversity ye Zimbabwe. Nguva dzekutamba dzichave mbiri mutsvakurudzo ino, nguva imwe, neimwe ichatarisirwa kutora maminitsi makumi matatu. Ruzivo rwuchatorwa harwuzogoveranwa kana nani zvake, kunze kwe Mutsvakurudzi , ndiye achakwanisa kuwana ruzivo rwuchanyorwa panguva yamuchabvunzwa mibvunzo. Nguva yese ichatamba mwana ichatorwa nevhidhiyo, asi hapana achazivikanwa nezita rake mukutorwa kwe vhidhiyo iyi, Ruzivo rwuchatorwa rwuchachengetwa pakachengetedzeka muhofisi inogara yakapfigwa nesvumbunuro.

Njodzi nekusagadzikana

Mutsvakurudzo ino, mutsvakurudzi ahabvunza mwana wako ne anotamba naye kuti vatambe vachitapwa. Munguva dzekuti matambiro evana angava nekukuvadzana vanotapa vanombomira potorwa madanho akafanira chiriporipocho. Imi kana mutsvakurudzi muchinzwa kuti munoda vamwe vanombotaura nemi kana vano kusumudzirai papfungwa, munozotumidzirwa kuChipatara che Parirenyatwa. Hurongwa hwerubatsiro rwakadaro hunorongwa mushure mekutanga kwetsvakurudzo.

Zvamungangowana kana/ muripo

Kupinda mutsvakurudzo ino kuzvipira kwenyu. Hapana mubhadharo wakanangana nekupinda mutsvakurudzo ino, asi vari mutsvakurudzo vachawana mari yekufambisa inokwana madhora mashanu. Mumwe nemumwe wevana vachapinda mutsvakurudzo vachapihwa chekutambisa chavanofarira kubva muimba yekutambira. Kupinda kwenyu mutsvakurudzo kunotarisirwa kuti kungabatsira kusimudzira kunzwisisa zviri maererano nematambiro ne nenzvimbo dzinotambirwa nevana vane zvirwere zvenguva refu. Zvinwiwa zvinozopihwa kuvanhu kupera kwechikamu chega, chega.

Kuzvipira kupinda mutsvakurudzo

Kana muchinzwa kuti hamudi kupinda mutsvakurudzo ino nechikonzero chipi zvacho makasununguka kuita saizvozvo.

Marapirwo nemabatirwo emazuva ese amungada haashandurwe neipi nzira zvayo. Munokwanisa kubuda mutsvakurudzo panguva ipi zvayo yamunoda pasina kumanikidzwa kupa chikonzero.

Zvakavanzika

Mutsvakurudzi neanomutevedzera havazoburitsa ruzivo rwurimaererano nemi kuna ani nani zvake asiri mumwe vevashandi vemutsvakurudzo.

Ruzivo rwuchawanikwa mutsvakurudzo ino rwuchachengetedzwa pakavanzika.

Ruzivo nezvenyu rwamuchapa rwuchave ne nhamba panzvimbo yekuisa zita renyu.

Vatsvakurudzi chete ndivo vachaziva nhamba yenyu, ruzivo urwu rwuchachengetedzwa panzvimbo yakachengeteka.

Nzira dzekubata Mutsvakurudzi

Kana mune mibvunzo ipi zvayo, munokwanisa kubvnza izvozvi kana munguva inotevera.

Kana muchida kuzobvunza mibvunzo panguva inotevera, munokwanisa kundibata, Mutsvakurudzi: Nyaradzai Munamba

Cell phone Number: +263 775 428 950

Address: University of Zimbabwe,

College of health Sciences

Department of Rehabilitation

Private Bag A198

Avondale, Harare

Munokwanisa kubata zvakare …….paUniversity muchishandisa ……

Elelwani Ramugondo telephone number +27 (0)21 650 2104, University of Cape Town.

Kana muchida kunzwisisa nezve kodzero dzenyu nemabatirwo evari mutsvakurudzo, ndapota batai mubati wechigaro we UCT bazi re Health Sciences Human Research Ethics Committee (HREC) vanonzi Muzvinafundo Marc Blockman- parunhare +27 (0)214066496

Kana muchida kunzwisisa nezve kodzero dzenyu nemabatirwo evari mutsvakurudzo, ndapota batai veMedical Research Council of Zimbabwe pa +263 784 956 128.

Kana kubvakachira mahofisi avo pakona pa Josiah Tongogara/ mugwagwa we Mazowe mu Harare, Zimbabwe.

7.12 APPENDIX L: Parent Informed Consent form (English)

School of Health and Rehabilitation Sciences

Faculty of Health Sciences

Divisions of Communications Sciences and Disorders, Nursing and Midwifery, Occupational Therapy, Physiotherapy

F45 Old Main Building, Groote Schuur Hospital,

Observatory 7925

Title of Project: **Comparing the differences and similarities of play profiles and play environments for children with and without specified chronic illness living in a low resourced setting of Zimbabwe.**

Principal Researcher: Nyaradzai Esther Munambah

Project Supervisors: A/Professor Elelwani Ramugondo and Professor Reinie Cordier

Institution: University of Cape Town, Department of Health and Rehabilitation Sciences

I the parent/ guardian of _____have read (or had information read to me by…….) and I that understand the study Nyaradzai Munambah wishes to do is about finding out if play for children with Chronic illness is different from that of typically growing children.

I hereby (*tick if yes and cross if no in appropriate boxes*)

- ☐ Give permission for my child to be involved in the study
- ☐ Give permission for my child to be video recorded for the study
- ☐ Do not give permission for my child to be involved in the study.
- ☐ I agree to being involved in this study
- ☐ I agree to being audio recorded during interview:

I have asked questions about the study and I am satisfied with the answers I obtained from the student. I am aware that the results of the study will remain confidential and the information will be presented to the University Of Cape Town but the identity of my child will be kept confidential and protected. I do understand fully what is required of me and I understand that we are not forced to be part of the study and we can withdraw at any point in time and there will be no consequence.

Parent/Guardian Full Name: _____

Signed

_____ _____

Participant Date and place

_____ _____

Researcher Date and place

_____ _____

Witness Date and Place

7.13 APPENDIX M: Parent Informed Consent form (Shona)

Gwaro Retenderano Remubereki

School of Health and Rehabilitation Sciences

Faculty of Health Sciences

Divisions of Communications Sciences and Disorders, Nursing and Midwifery, Occupational Therapy, Physiotherapy

F45 Old Main Building, Groote Schuur Hospital,

Observatory 7925

Musoro we Tsvakurudzo**; Comparing the differences and similarities of play profiles and play environments for children with and without specified chronic illness living in a low resourced setting of Zimbabwe.**

Mutsvakurudzi Mukuru: Nyaradzai Esther Munambah

Varairidzi: A/Professor Elelwani Ramugondo and Professor Reinie Cordier

Chikoro: University of Cape Town, Department of Health and Rehabilitation Sciences

Ini mubereki/ muchengeti wa…….ndaverenga (kana kuti ndavarengerwa na……) uye ndanzwisisa kuti tsvakurudzo inoda kuitwa na Nyaradzai Munambah iri pamusoro pekuongorora kuti matambiro evana vane chirwere chenguva refu akasiyana here neevana vanokura vasina zvinetswa.

I hereby (*tick if yes and cross if no in appropriate boxes*)

Sarudzai hongu nekuisa tiki kana kwete nekuisakirosi mumabhokisi akafanira

- ☐ Ndinopa mvumo yekuti mwana wangu apinde mutsvakurudzo
- ☐ Ndinopa mvumo yekuti mwana wangu atorwe vhidiyo yemutsvakurudzo
- ☐ Handipe mvumo yekuti mwana wangu apinde mutsvakurudzo
- ☐ Ndinobvuma kupinda mutsvakurudzo
- ☐ Ndinobvuma kutapwa panguva yekubvnzwa mibvunzo:

Ndabvunza mibvunzo iri maererano netsvakurudzo, ndagutsikana nemhinduro dzandawana kubva kumudzidzi. Ndinonzwisisa kuti zvichawanikwa mutsvakurudzo zvicharamba zvakawanzika uye ruzivo urwu rwuchapihwa kuUniversity yeCapetown. Zvose zviri maerano

nemwana wangu zvichachengetwa zvakavanzika pakachengetedzwa. Ndanyatsonzwisisa zvinodiwa kubva kwandiri uye ndinonzwisisa kuti hatimanikidzwe kupinda mutsvakurudzo uye tinokwanisa kubuda paneipi nguva zvayo pasina zvakaipa zvinozoitika.

Mubereki/Muchengeti Zita Rakazara _____

Sainecha

_____ _____

Arimutsvakurudzo Zuva ne Nzvimbo

_____ _____

Mutsvakurudzi Zuva ne Nzvimbo

_____ _____

Chapupu (Witness) Zuva ne Nzvimbo

7.14 APPENDIX N: Assent forms for child participants

School of Health and Rehabilitation Sciences

Faculty of Health Sciences

Divisions of Communications Sciences and Disorders, Nursing and Midwifery, Occupational Therapy, Physiotherapy

F45 Old Main Building, Groote Schuur Hospital,

Observatory 7925

Information

This study involves seeing you playing with your friend. This will help in understanding how play is similar or different in children with illness for a long time (chronic) compared to those without long term illness in Zimbabwe.

I am  happy to be part of the study

I am  unhappy to be part of the study

Please circle the first face if you would like to be part of this study, or circle the second face if you would not like to be part of this study.

Signed

Parent /Guardian	Date and place
Researcher	Date and place
Witness	Date and Place

7.15 APPENDIX O: Assent forms for child participants (Shona)

Fomu revana vapinda mutsvakurudzo huru:

School of Health and Rehabilitation Sciences

Faculty of Health Sciences

Divisions of Communications Sciences and Disorders, Nursing and Midwifery, Occupational Therapy, Physiotherapy

F45 Old Main Building, Groote Schuur Hospital,

Observatory 7925

Ruzivo

Tsvakurudzo ino inosanganisira kukuona uchitamba neshamwari yako.Izvi zvinobatsira pakunzwisisa kufanana kana kusiyana kwematambiro muvana vane chirwere chenguva refu vachienzaniswa nevasina chirwere chenguva refu mu Zimbabwe.

Ndinofara kuva mumwe ari mutsvakurudzo

Handifari kuva mumwe ari mutsvakurudzo

Ndapota itai denderedzwa rakatenderedza meso uripekutanga kana uchida kuva mumwe wevamwe vari mutsvakurudzo ino, kana kuti ita denderedzwa rakatenderedza meso wechipiri kana usingadi kuva mumwe wevari mutsvakurudzo ino.

Sainecha _____ _____

Mubereki/ Muchengeti

Zuva ne Nzvimbo

Mutsvakurudzi

Zuva ne Nzvimbo

Chapupu

Zuva ne Nzvimbo

7.16 APPENDIX P: Questionnaire on Demographics of the caregiver and the child

School of Health and Rehabilitation Sciences

Faculty of Health Sciences

Divisions of Communications Sciences and Disorders, Nursing and Midwifery, Occupational Therapy, Physiotherapy

F45 Old Main Building, Groote Schuur Hospital,

Observatory 7925

Demographic data:

Administrated by: _____

Participant number/code: _____

Instructions: Please read the questions carefully and answer according to what applies to you and your family. Please ensure you answer all the questions. If you need any clarification on a question please ask the researcher or assistant to help you. Some questions require you to tick the relevant box related to your answer and other questions require you to write in your response. Please read the question to know whether you should tick only ONE option – if more than one option applies tick the one that applies the most. Some question will say that you can tick more than one option. If you make a mistake and mark the incorrect box, clearly scratch out the box and tick the new, correct answer. Please be as truthful as possible in answering these questions. Remember your results are kept confidential.

SECTION A: CAREGIVER'S DETAILS

1. What is YOUR (caregiver) age range in years? Age _____(years)_____

2. **What is YOUR (caregiver) gender? (*Please tick your answer) gender***

Male ☐ Female ☐

3. What is YOUR (caregiver) highest level of education COMPLETED? Tick ONE answer.

None ☐

Primary School(Grade 1- 7) ☐

ZJC (Form1 and 2) ☐

O level (form 3 and 4) ☐

A level (form 5 and 6) ☐

B. degree ☐

Master's Degree ☐

PhD ☐

4. Are you the biological parent of the child?

Yes ☐

No ☐

5. If you answered 'no' to the above question, what is your relationship with the child?

Grandparent ☐

Aunt / uncle ☐

Sister / brother ☐

Foster parent ☐

Other. Please specify _____

6. How much time during the week are you usually with your child? This refers to time awake with the child therefore does not include sleeping time. Please tick only ONE answer. Length of time

Less than 7 hours per week ☐

8 to 20 hours per week ☐

more than 20 hours per week (most of your time is spent with the child) ☐

7. How many children (including children from extended family) under the age of 18 do you take care of, in total (including child attending clinic)?

_____

8. How old are the other children in the house? Fill in the children's ages in the gaps below.

Age of child 1: _____; age of child 2: _____; age of child 3: _____; age of child 4 _____;

age of child 5: _____; age of child 6: _____; age of child 7: _____ 11. _____

9. How many other adults over the age of 18 do you live with at home?

_____

10. What is the total amount of money that you and your family (who you live with) live off every

month? This INCLUDES salaries, grants and all other sources of income. Tick ONE answer.

No income ☐

$1 - $100 ☐

$101 - $200 ☐

$201 - $300 ☐

$301 - $400 ☐

$401 - $500 ☐

$501 - $600 ☐

$701 - $800 ☐

$801 - $900 ☐

$901 - $1000 ☐

$1001 or more ☐ specify amount _____

11. What is YOUR (caregiver) status/ level of employment? Tick all that apply.

Unemployed: ☐

Looking for work: ☐

Stay at home mom/daddy: ☐

parent Retired: ☐

Self-employed: ☐

Part-time employment: ☐

Full-time employment: ☐

Seasonal/occasional employment ☐

Other specify_____

SECTION B: CHILD'S DETAILS

12. What is your child's date of birth? _____

13. How many weeks were you/the biological mother pregnant when the child was born?

Under 29 weeks. The child was born very early (very premature) ☐

29 to 36 weeks. The child was born early (premature) ☐

37 weeks or more. The child was born at full term. ☐

I do not know ☐

14. Were there any problems both to the child and the mother during birth?

Yes. ☐

No. ☐

I don't know. ☐

If yes, please specify

_____

_____

15. What is the confirmed (by the doctor) medical diagnosis of **the child?**

Cancer ☐

HIV+ ☐

Chronic respiratory disease ☐

16. Are there any other confirmed (by the doctor) medical diagnosis of the child, other than one(s) mentioned above?.

No. ☐

I don't know ☐

Yes. ☐

If yes, please specify_____

17. Where is your child USUALLY during the day in the week? Tick ONE answer?

My child attends crèche/play school ☐

My child attends formal school ☐

My child stays with me during the day ☐

My child goes to another friend/family member/day mother during the day ☐

18. If your child is in school, what grade is he/she in?

Crèche ☐

ECD A ☐

ECD B ☐

Grade 1 ☐

Grade 2 ☐

Grade 3 ☐

My child is not in school. ☐

19. Where (space/area) does your child mostly play at?

At school (play grounds) ☐

Inside house ☐

Outside house around the yard ☐

On the streets ☐

Parks ☐

20. If your child plays in the house, where inside the house does your child play (if they are allowed to play inside)?

_____

_____

21. Who is the MAIN person who plays with the child (most of the time)? Tick ONE answer.

The child mainly plays by himself/herself ☐

You, the caregiver ☐

Another adult (over 18 years) ☐

A younger child in your house ☐

An older child in your house (that is younger than 18 years) ☐

Another child outside the house eg (neighbour or friend) ☐

22. What are 3 of your child's favourite toys/things that s/he plays frequently with?

1. _____

2. _____

3. _____

Section C: World Health Organisation Disability Assessment Schedule (WHODAS) version 2.0; questions on getting about

Getting around

In the past 30 days, did your child experience any difficulty in:	**None**	**Mild**	**Moderate**	**Severe**	**Extreme**	**cannot do**
Standing for long periods such as 30 minutes?						
Standing up from sitting down?						
Moving around inside your home?						

Getting out of your home?

Walking a long distance such as a

kilometre [or equivalent]?

SECTION D: INFORMATION FROM FILE OR ROAD TO HEALTH CARD

THIS PAGE IS TO BE FILLED IN BY RESEARCHER

Separate page of info to get from file or Road to Health card

Participant Code: _____

Birth History

23. Gestation_____
24. Birth weight:
    _____
25. Apgar 1min:
    5min:
    not recorded_____
26. Birth delivery:
    NVD;
    C/S;
    Unknown _____
27. Birth complications
    No problems;
    Problems. Specify:_____

_____

Medical History

28. Date child was diagnosed of his/her condition
    _____
29. Date started medication/treatment for his/her condition_____
30. Defaults History _____
31. Other Diagnoses No Yes: specify: _____

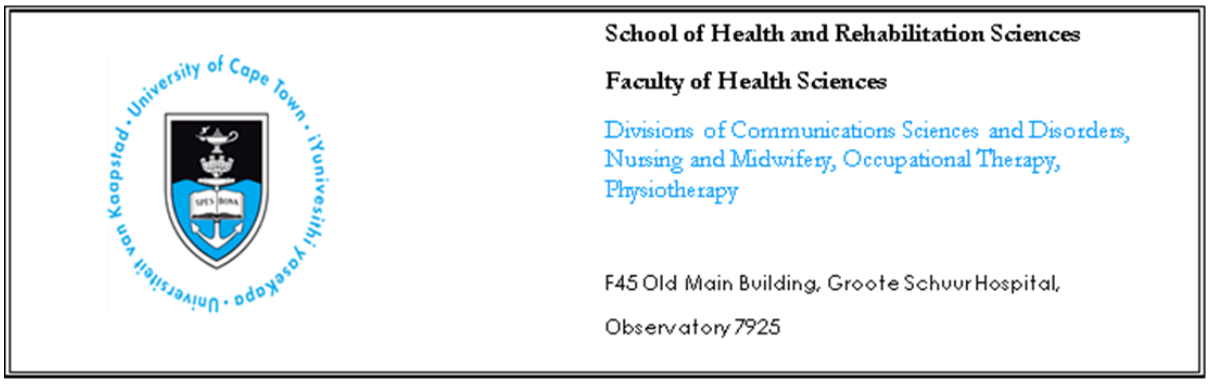
Complimentary services

32. Other Health services attended in past.

_____

_____

7.17 APPENDIX Q: Questionnaire on Demographics of the caregiver and the child (Shona)



Demographic data:

Administrated by: _____

Nhamba yeari mutsvakurudzo:

Zvekuita;

Ndapota verengayi mibvunzo nemazvo nekupindura zvirimaererano nezvinoenderana nemi nemhuri yenyu.

Ndapota onayi kuti mapindura mibvunzo yese. Kana muchida kujekeserwa pane upi zvawo mubvunzo ndapota bvunzai mutsvakurudzi kana anomubatsira kuti akubatsireyi.

Mimwe mibvunzo inoda kuti murakidzire nekutika mubhokisi rinoenderane nemhinduro yenyu, mimwe mibvunzo inoda kuti munyore nemafungiro enyu.

Ndapota verengayi mubvunzo kuti muzive kana muchifanira kutika sarudzo imwe chete – kana sarudzo ichipfuura imwe chete sarudza yakanyanyisa kukodzera.

Mimwe mibvunzo inoti munokwanisa kutika mikana inopfuura mumwe chete.

Kana makakanganisa makamaka bhokisi risiriiro, nyatsodzimai bhokisi racho motika mhinduro itsva yakafanira.

Ndapota ivai pachokwadi chakazara pakupindura mibvunzo iyi. Rangarirai zvichabuda mutsvakurudzo zvichachengetedzwa zvakavanzika.

CHIKAMU A: Zvinechekuita nemuchengeti

1. Muchengeti wako angave nemakore mangani ? Makore……..

2. **Muchengeti wako munhuyi? (Ndapota tikai mhinduro)**

Murume ☐

Mukadzi ☐

3. Mucheneti wenye akadzidza kusvika pachidanho chipi chezvedzidzo? Sarudza mhinduro imwechete.

Haana kudziidza ☐

Dzidzo yekutanga ☐

Fomu yekutanga neyecipiri ☐

Dzidzo yepamusoro (Fomu yechitatu neyechina) ☐

Dzidzo yepamusorosoro (Fomu yechishanu neyechitanhatu) ☐

DHigirii ☐

Dhigirii repamusoro ☐

DHigirii repamusorosoro ☐

4. Ndimi mubereki akazvara mwana uyu here?

Hongu ☐

Kwete ☐

5. Kana mapindura kuti ‘ kwete’ kune mubvunzo uripamusoro apa, mune hukama hupi nemwana?

Muzukuru ☐

Tete/ Sekuru ☐

Hanzvadzi Sikana/ Hanzvadzi Komana ☐

Zimwewo. Tsanangurai _____

6. Mune nguva yakareba sei pakati pesvondo yamunowanza kuva nemwana wenyu? Izvi zvirikurevera nguva yamunenge makasvinura zvisingasanganisire nguva yekurara. Sarudzai mhinduro imwe chete. Kureba kwenguva

Kushure kwemaawa manomwe pasvondo ☐

Maawa masere kisvira makumi maviri pavhiki ☐

Kupfuura maawa makumi maviri pavhiki (Nguva yenyu yakawanda inopera mune mwana) ☐

7. **Vana vangani (Kusanganisira vana vehukama) varipasi pemakore gumi nemasere vamunochengeta, pamwechete (kusanganisira mwana arikuenda kukiriniki)?**

_____

8. **Vana vakuru mumba umu vanemakore mangani?**

Makore emwana wekutanga: ……; makore emwana wechipiri: ……; makore emwana wechitatu:……; makore emwana wechina

Makore emwana wechishanu:……; makore emwana wechitanhatu:……..; makore emwana wechisere

9. **Kune vamwe vangani vakuru vane makore ari pamusoro pegumi nemasere vamunogara navo kumba?**

_____

10. **Mari yamunoshandisa kurarama pamwedzi wega wega imi nemhuri (vamunogara navo) yenyu pamwechete yakawanda seyi?**

Hapana mari ☐

Dora rimwechete kusvika kuzana remadhora ☐

Zana rimwechete, remadhora ne dhora rimwechete kusvika mazana maviri ☐

Mazana maviri nedhora rimwechete kusvika mazana matatu emadhora ☐

Mazana matatu nedhora rimwechete kusvika mazana mana emadhora ☐

Mazana mana nedhora rimwechete kusvika mazana mashanu emadhora ☐

Mazana mashanu nedhora rimwechete kusvika mazana matanhatu emadhora ☐

Mazana manomwe nedhora rimwechete kusvika mazana masere emadhora ☐

Mazana masere nedhora rimwechete kusvika mazana mapfumbamwe emadhora ☐

Mazana pfumbamwe nedhora nerimwe chete kusvika churu chimwete chemadhora ☐

Churu chimwechte nedhora rimwechete nekupfuurira ☐

Tsanangura huwandu……

11. Muchengeti wako ari pachidanho chakasvika papi kubasa? Sarudza zvese zvakakodzera

Haasi pamushando: ☐

Ari kutsvaga basa: ☐

Vanogara pamusha amai/ baba: ☐

Mubereki akasiya basa nekukwegura: ☐

Vanozvishandira: ☐

Vanoshanda apo neapo: ☐

Vanoshanda nguva yakazara: ☐

Vanoshanda pane dzimwe nguva dzepagore: ☐

Zvimwe Tsanangura _____

CHIKAMU B: Ruzivo rwakanangana ne mwana

12. Mwana wenyu akaberekwa rinhii? _____

13. Mangamune masvondo mangani epamuviri/ amai vakatakura pamuviri kusvika pakazvarwa mwana?

Pasi pemasvondo makumi maviri nemapfumbamwe. Mwana akazvarwa nguva isati yakwana zvakanyanya (gava mwedzi rakanyanya) ☐

Makumi maviri nemapfumbamwe kusvikira makumi matatu nematanhatu emasvondo ☐

Masvondo makumi matatu nemanomwe zvichipfuurira. Mwana akazvarwa nguva yasvika ☐

Handizivi ☐

14. Pane madambudziko here akawanikwa kuna amai zvese nemwana panguva yekusununguka

Hongu ☐

Kwete ☐

Handizivi ☐

Kana mhinduro iri hongu, ndapota tsanangurayi.

_____

_____

15. **Ndechipi chirwere chakawanika pamwana navanaChiremba vehutano?**

Gomarara ☐

Hutachiwana hwe HIV ☐

Chirwere chemapapu kwenguva yakareba ☐

16. Pane zvimwe zvirwere zvakawanikwa here navana chiremba pamwana kunze kwezvataurwa pamusoro apo

Hapana ☐

Handizive ☐

Hongu ☐

Kana iri hongu tsanangurai

_____

17. Mwana wenyu anenge arikupi nguva yakawanda pakusvera kwezuva pasvondo?

Mwana wangu anoenda kukireshi/ kana kuchikoro kwekunotamba ☐

Mwana wangu anoenda kuchikoro ☐

Mwana wangu anosvera neni pakusvera kwezuva ☐

Mwana wangu anoenda kweshamwari/ kwemumwe we mumhuri/ kwevamwe amai pakusvera kwezuva ☐

18. **Kana mwana wenyu achienda kuchikoro ari mudanho rechingani?**

Damba revana ☐

Chikamu chekutanga chekukura kwemwana ☐

Chikamu chechipiri chekukura kwemwana ☐

Gwaro rekutanga ☐

Gwaro rechipiri ☐

Gwaro rechitatu ☐

Mwana wangu haapindi chikoro ☐

19. Mwana wenyu anowanzo tambira payi? ☐

Kuchikoro (nhandare inotambira vana) ☐

Mukati memba ☐

Kunze kwemba pachivanze ☐

Mumigwagwa ☐

20. Kana mwana wenyu achitambira mumba, ndepapi mumba paanotambira (Kana vachibvumidzwa kutambira mumba)?

_____

_____

21. Ndiyani munhu anonyanyotamba nemwana (nguva zvinji)? Sarudza mhinduro imwechete

Mwana anowanzozvitambira pachake ☐

Iwe, muchengeti ☐

Mumwe munhu mukuru (anemakore anopfuura gumi nemasere) ☐

Mwana mudiki ari mumba menyu ☐

Mwana mukuru ari mumba menyu (anemakore aripasi pegumi nemasere) ☐

Mumwe mwana wekunze sekuti (wevawakidzani kana shamwari) ☐

22. Ndezvipi zvitatu zvekutambisa zvinowanzo farirwa nemwana wenyu, zvinhu zvaanowanzo tamba nazvo?

1. _____

2. _____

3. _____

CHIKAMU C: World Health Organisation Disability Assessment Schedule (WHODAS) version 2.0;

Mibvunzo yekuenderera mberi

Kuenderera mberi

Mumazuva makumi matatu apfuura, mwana wenyu akambonetseka here neizvi:	**Hapana**	**Zvishoma**	**Zviripati nepakati**	**Zvakanyanya nekupfuuridza**	**Zvingakwanisike**
Kumira kwenguva refu semaminitsi makumi ma matatu?					
Kusumuka mukubva mukugagra pasi?					
Kufamba,famba muchitenderera mumba menyu?					
Kubuda mumba menyu?					
Kufamba nhambo refu sekunge kiromita (kana zvakaenzana)					

CHIKAMU D: RUZIVO KUBVA MUMAGWARO EKADHI RE ROAD TO HEALTH

Peji rakasiyana reruzivo rinowanikwa mumagwaro kana mukadhi re Road to Health

Nhamba ye arimutsvakurudzo_____

Nhoroondo yekuzvarwa

a) Gestation_____

b) Huremu pakuberekwa

_____

C) Zvibodzwa zvekuchema kwe mwana kwapera miniti rimwechete:

Maminitsi mashanu:
Zvisina kunyorwa_____

D) Nzira dzekusununguka
E) Kusununguka zvakanaka
F) Kusununguka nekuchekwa

_____

Hazvizivikanwe

G) Zvinetswa pakusununguka_____

Hapana zvinetswa:_____
Zvinetswa. Tsanangurayi:

_____

Nhoroondo yezveutano

H) Zuva rakabatwa chirwere chemwana_____
I) Zuva rakatangwa mushonga/ kurapwa kwechirwere chemwana_____
J) Nhorondo yezvinotarisirwa_____
K) Zvimwewo zvirwere Hongu Kwete: Tsanangura:
_____

Dzimwe nzira dzekubatsira

A) Dzimwe nzira dzehutano dzakamboshandiswa munguva yakapfuura

_____

_____

7.18 APPENDIX R: Test of Playfulness

TEST OF PLAYFULNESS (ToP) (Version 4.0–5/05)

Child (#): _____ Age: _____ Rater: _____ In Out Video Live (Circle)	EXTENT 3 = Almost always 2 = Much of the time 1 = Some of the time 0 = Rarely or never NA = Not Applicable	INTENSITY 3 = Highly 2 = Moderately 1 = Mildly 0 = Not NA = Not Applicable	SKILLFULNESS 3 = Highly skilled 2 = Moderately skilled 1 = Slightly skilled 0 = Unskilled NA = Not Applicable

ITEM	EXT	INT	SKILL	COMMENTS
Is actively engaged.				
Decides what to do.				
Maintains level of safety sufficient to play.				
Tries to overcome barriers or obstacles to persist with an activity.				
Modifies activity to maintain challenge or make it more fun.				
Engages in playful mischief or teasing.				
Engages in activity for the sheer pleasure of it (process) rather than primarily for the end product.				
Pretends (to be someone else; to do something else; that an object is something else; that something else is happening).				
Incorporates objects or other people into play in unconventional or variable **and** creative ways.				
Negotiates with others to have needs/ desires met.				
Engages in social play.				
Supports play of others.				
Enters a group already engaged in an activity.				
Initiates play with others.				
Clowns or jokes.				
Shares (toys, equipment, friends, ideas).				
Gives readily understandable cues (facial, verbal, body) that say, "This is how you should act toward me."				
Responds to others' cues.				
Demonstrates positive affect during play.				
Interacts with objects.				
Transitions from one play activity to another with ease.				

Figure 4-9
ToP protocol sheet.

7.19 APPENDIX S: Interview Guide

Interview Guide Protocol

Project Title: Comparing the differences and similarities of play profiles and play environments for children with and without specified chronic illness living in a low resourced setting of Zimbabwe'

Objectives:

1. To describe the barriers and facilitators of play for children with chronic illness in a low resource setting as perceived by caregivers.
2. To describe caregivers' experience of promoting play for children with chronic illness in a low resource setting.

Time of interview:

Date:

Place:

Interviewer:

Interviewee:

Demographic Information of the participant:

Marital Status:……..

Level of Education:……..

Occupation:……..

Average income per month……...

How many children do you have?.....

Number of children on ART treatment:……..……..

Questions:

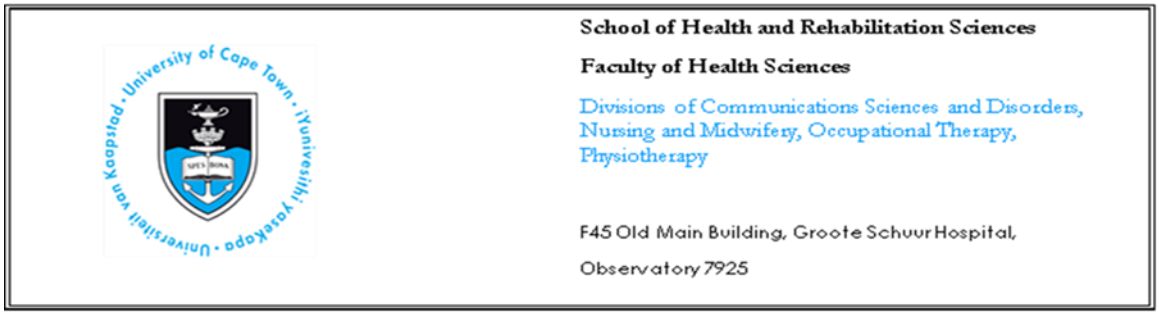
1. How does your child play in most of the times?
2. Is the play any different from other children in your area? If so please explain.
3. How is play of your child similar or different when compared to other children in your area
4. What really makes the play to be similar or different when compared to other children in your area
5. Do you often engage in play with your child? If yes, please explain how you play with your child
6. Apart from you, who else (adults) play with the child at home?
7. What are the things that make it easy or make children want to engage in play?
8. What are the things that hinder or make it difficult for the children to play?
9. How do you promote play of your child?

10. What are the challenges that you experience in promoting play for your child?

11. In your opinion, what can be done to promote play for children with chronic illness in Zimbabwe?

(Thank you for participating in this interview. All information discussed is confidential and will be handled with utmost care. Once again thank you)

7.20 APPENDIX T: Delphi study Participant Information Statement



HREC Project Number:640/2017

Project Title: Comparing the differences and similarities of play profile for children with and without HIV/Aids

Principal Investigator: Prof Elelwani Ramugondo & Prof Reinie Cordier

Student Investigator: Nyaradzai Munambah

Version Number: Version 1

Version Date: 27/01/2020

What is the Project About?

Due to the advent of antiretroviral therapy, there has been increasing numbers of children infected with HIV who are living beyond toddler stage into infants through to adulthood. The efforts of saving the children's lives need to be complimented by availing opportunities for children to live meaningful lives. However, previous research has shown that children with HIV/Aids are likely to have reduced levels of playfulness as compared to typically developing children. Deprivation of play itself or opportunities for children to be playful can be detrimental to the life of these children. Through play children learn essential skills for adulthood. We wish to investigate playfulness in children with HIV/Aids comparing the similarities and differences to typically developing children with the aim of developing guidelines for promoting play in children with HIV/Aids in Zimbabwe. The guidelines will be used by professionals who work with children with HIV/Aids and be able to be in cooperated in programs run for/with the children.

The overall project is in four phases. The first phase involved review of literature on play of children with health and developmental disorders and disabilities. In the second phase playfulness of children with HIV was measured (indoors and outdoors) using the test of Playfulness and compared to age and gender matched typically developing children. The third phase was in depth interviews with caregivers pf children with HIV (participated in phase 2 of the study) on their perspectives of their children's play and also gave their opinions of what should be done to promote play in children with

HIV/Aids. The fourth phase involves asking experts on play, HIV/Aids and intervention development on development of guidelines for promoting playfulness in children living with HIV/Aids in low resourced settings.

Who is doing the Research?

The project is being conducted by Nyaradzai Munambah, under the supervision of Prof Elelwani Ramugondo and Prof Reinie Cordier. The results of this research project will be used by Nyaradzai Munambah to obtain a Doctor of Philosophy at University of Cape Town.

Why am I being asked to take part and what will I have to do?

We are looking for experts in the field of HIV/Aids, play and/or intervention development. You have been asked to take part because you are a:

- Allied health professional with experience working with students with HIV/Aids;

- Service provider that has a model of service delivery whereby you use play as a medium of intervention for children;

- Research academic with experience in HIV/Aids, play and/or intervention development;

- Leadership staff within the Opportunistic Infections Clinics, Department of Education, Peadiatrics and Organisations that work with children with HIV/Aids.

You have been asked to take part because of your knowledge and expertise in the topic area. You will be asked to participate in a series of online questionnaires called a Delphi study. This will help us to obtain a consensus from experts in the field regarding components to be included in the intervention. The first questionnaire will include likert scale and open-ended questions. Subsequent questionnaires will include only Likert scale survey questions in order for us to reach a consensus. The number of questionnaires will depend on when experts reach a consensus – that is, when at least 70% of Delphi participants rate three or higher on a 5 point Likert scale. After each round of questionnaires, you will be provided with a summary of findings from the previous round, and asked to review your decisions or specify the reasons why you remain outside of the consensus. All information will be de-identified. There will be no cost to you for taking part in this research.

Are there any benefits' to being in the research project?

There may be no direct benefit to you from participating in this research. Sometimes, people appreciate the opportunity to discuss their thoughts and opinions and share their expertise. We hope the results of this research will help us to develop guidelines for promoting playfulness in children with HIV/Aids.

Are there any risks, side-effects, discomforts or inconveniences from being involved in the research project?

There are no foreseeable risks from this research project. Apart from giving up your time, we do not expect that there will be any risks or inconveniences associated with taking part in this study.

Who will have access to my information?

Any information we collect will be treated as confidential and used only in this project unless otherwise specified. Only the research team will have access to the information. The information collected in this research will be de-identifiable which means we will remove identifying information on any data and replace it with a code. The code will be stored separately from the participant data. Hardcopies of the information we collect in this study will be kept under secure conditions in the Department of Rehabilitation, University of Zimbabwe (where Nyaradzai is based). Electronic data will be password-protected and hard copy data (including audio tapes) will be in locked storage. It will be kept for a period of 7 years after the research has ended and then it will be destroyed. You have the right to access, and request correction of, your information in accordance with relevant privacy laws. The results of this research may be presented at conferences or published in professional journals. You will not be identified in any results that are published or presented.

Will you tell me the results of the research?

We will send you a summary of the findings from the study and detail how these findings will contribute towards the development of the intervention. You should receive these results within 3 months of participating in the research. We will also make the results available through publication in scientific peer reviewed journals.

Do I have to take part in the research project?

Taking part in a research project is voluntary. It is your choice to take part or not. You do not have to agree if you do not want to. If you decide to take part and then change your mind, that is okay, you can withdraw from the project. You do not have to give us a reason; just tell us that you want to stop. If you chose to leave the study we will use any information collected unless you tell us not to.

What happens next and who can I contact about the research?

If you decide to take part in this research we will ask you to sign the consent form. By signing the consent form, it is telling us that you understand what you have read and what has been discussed. Signing the consent indicates that you agree to be in the research project. Please take your time and ask any questions you have before you decide what to do. You will be given a copy of this information and the consent form to keep. If you have any questions or would like to discuss the

research further you can contact Nyaradzai Munambah on dngnya002@myuct.ac.za or +263 775 428 950.

University of Cape Town Human Research Ethics Committee (HREC) has approved this study (HREC number 640/2017). Should you wish to discuss the study with someone not directly involved, in particular, any matters concerning the conduct of the study or your rights as a participant, or you wish to make a confidential complaint, you may contact the Chairperson of the UCT Faculty of Health Sciences Human Research Ethics Committee (HREC) is Professor Marc Blockman - telephone number +27 (0)21 406 6496 at University of Cape Town.

If you have concerns about human rights and welfare of the research participants, Please Contact the Medical Research Council of Zimbabwe on +263 784 956 128, or to visit their offices at Corner Josiah Tongogara/ Mazowe Street, Harare, Zimbabwe.

7.21 APPENDIX U: First Round Delphi Questionaire

Experts informed CONSENT

Thank-you for participating.

This survey is for invited participants only. Before proceeding with this survey, you must consent to participate in this study. Please read the information below and respond accordingly.

I understand the aim of this Delphi study is to gain a consensus from experts in the field of HIV/Aids, play and/or intervention development on the:

- Development of play based interventions to promote playfulness in children with HIV/Aids;
- The content, delivery and feasibility of a play based intervention.

I consent to participate in this project, the details of which have been explained to me, and I have been sent (via email) a written information statement to keep.

I understand that:

- My participation will involve approximately three Delphi rounds completed via an online survey.
- My de-identified survey responses will be provided to other participants during the Delphi process.
- De-identified data from the surveys may be used by the researchers in publications (as described in the information statement).

I acknowledge that:

- Taking part in this study is voluntary and I am aware that I can stop taking part at any time without explanation or prejudice.
- My name will not be used to identify my survey responses.

*

I consent to complete an online survey and for my response to be used for the purposes described above

- ○ Yes (1)
- ○ No (2)

Page Break

End of Block: INFORMED CONSENT

Start of Block: ELIGIBILITY

ELIGIBILITY

The following questions ask you to confirm your eligibility to participate in this survey. If you have any questions or concerns, please email dngnya002@myuct.ac.za .

PPENDIXES: Online questionnaire to experts

Have you spent more than 5 years (full-time equivalent) in the last 10 years working with children living with HIV/Aids, OR play based activities with children?

For the purpose of this study:

- Children living with HIV/Aids refer to children aged between 4 and 10 years of age, who have been diagnosed as HIV Positive by a medical doctor and maybe or may not be on antiretroviral therapy.
- Play based Activities related to children include:
    - Provision of clinical services (where approximately 50% or more of caseload is children aged 4 and 10 years or using play based interventions)
    - Research (where approximately 50% or more of research on play based interventions or research activities related to children aged 4 and 10 years).
    - Staff development/training, academic teaching, resource development or consultancy (where approximately 50% or more of professional activities relate to services for children aged 4 and 10 years).
    - Combination of the above.

○ Yes (1)

○ No (2)

Page Break

End of Block: ELIGIBILITY

Start of Block: INSTRUCTIONS

INSTRUCTIONS

The survey should take **approximately 30 minutes to complete**, however this may vary depending on your responses.

All questions are mandatory.

Remember that **you can leave this survey (multiple times) and come back later to where you left off**, if you use the same computer and same web-browser each time. You do not have to click a "save" button, just close the survey window and use the link to open the survey up again later.

It is recommended that you **use a desktop computer** to complete the survey (not your mobile), as you will be required to open and refer to a document regularly throughout the survey.

Please make sure you read information carefully before responding to questions in the survey.

End of Block: INSTRUCTIONS

Start of Block: DEMOGRAPHICS AND PROFESSIONAL BACKGROUND

PART ONE - DEMOGRAPHICS AND PROFESSIONAL BACKGROUND

The purpose of this part of the survey is to gather information on the demographics of experts participating in the Delphi.

Please indicate gender

- ○ Male (1)
- ○ Female (2)
- ○ Other (3)
- ○ Prefer not to say (4)

Please indicate age.

- ○ 20-29 (1)
- ○ 30-39 (2)
- ○ 40-49 (3)
- ○ 50-59 (4)
- ○ 60-69 (5)
- ○ 70-79 (6)
- ○ >80 years (7)

Which country do you live in?

- ○ America (1)
- ○ Australia (2)
- ○ Malawi (3)
- ○ New Zealand (4)
- ○ South Africa (5)
- ○ United Kingdom (6)
- ○ Tanzania (7)
- ○ Other, please specify (8) _____

Please indicate the option(s) that best describe the sector(s) in which you are currently employed. Select a maximum of 2 options.

- [ ] Service Provider (i.e. government or non-government school aged service provider) (1)
- [ ] Education Sector (i.e. government or non-government education department) (2)
- [ ] Private Practice/ Small Business (3)
- [ ] University (4)
- [ ] Currently a student (i.e. Masters or PhD) (5)
- [ ] Other agency (i.e. government or non-government) (6)
- [ ] Other, please specify (7) _____

Please indicate the option(s) that best describe your profession/role. Select all that apply.

- [ ] Teacher (1)
- [ ] Doctor (various specialties) (2)
- [ ] Principal (3)
- [ ] Learning Support Coordinator (4)
- [ ] Education Assistant (5)
- [ ] Speech Pathologist (6)
- [ ] Occupational Therapist (7)
- [ ] Psychologist (8)
- [ ] Case Manager (9)
- [ ] Researcher / Academic (10)
- [ ] School Aged Service Provider (11)
- [ ] Other, please specify (12) _____

Please indicate your (Highest) qualifications.

- ○ Certificate (1)
- ○ Diploma (or equivalent) qualification (2)
- ○ Bachelor (or equivalent) degree (3)
- ○ Master's degree, please specify (4) _____
- ○ PhD (research) (5)
- ○ Other, please specify (6) _____

Please indicate the total number of years (full time equivalent) you have of working experience.

- ○ 0 - 1 years (1)
- ○ 2 - 3 years (2)
- ○ 4 - 5 years (3)
- ○ 6 - 7 years (4)
- ○ 8 - 9 years (5)
- ○ >10 years, please specify (6)

_____

Please indicate how many years' of experience (full time equivalent) you have had working with children living with HIV/Aids <u>OR</u> using play based activities with children.

- ○ 0 - 1 years (1)
- ○ 2 - 3 years (2)
- ○ 4 - 5 years (3)
- ○ 6 - 7 years (4)
- ○ 8 - 9 years (5)
- ○ >10 years, please specify (6)

_____

End of Block: DEMOGRAPHICS AND PROFESSIONAL BACKGROUND

Page Break

Start of Block: GENERAL QUESTIONS RE: PLAY BASED INTERVENTION AND HIV/AIDS

PART TWO - GENERAL QUESTIONS ABOUT HIV/AIDS AND PLAY BASED INTERVENTION

The purpose of this part of the survey is to get your opinion on play based intervention for children with HIV/Aids. Your knowledge and experience in the area is extremely valued.

In your experience, which of the following challenges do children with HIV/Aids likely experience when playing?

- ○ Not feeling well (1)
- ○ Fatigue easily (2)
- ○ Not skilled enough to play (3)
- ○ Not able to express themselves clearly to playmates(4)
- ○ Lack of friends/playmates (5)
- ○ Other specify (5)

_____
_____
_____

In your setting, in which you are currently involved, what processes and/or techniques do you use to promote the participation of children with HIV/AIDS in play based interventions?

- ○ Therapist Modelling
- ○ Peer modelling
- ○ Video Modelling
- ○ Caregiver education
- ○ Process of decentering [Explain in brief perhaps?]Sarah's article
- ○ Other specify_____

_____

Is there anything you can think of that would be useful to facilitate the playfulness of children with HIV/Aids that is not already in place or currently being offered in your setting?

- ○ Provision of toys (1)
- ○ Promoting compliance (2)
- ○ Provision of food (3)
- ○ Provision of safe spaces to play (4)
- ○ Other specify (5)_____

_____

End of Block: GENERAL QUESTIONS RE: HIV/Aids AND PLAY BASED INTERVENTION

PART THREE – a conceptual framework: Descriptive model of children's play:

The purpose of this part of the survey is to get your opinion on the application of the descriptive model of children's play that was developed by Cooper (2000) to critically examine the impact of child abuse on children's play. The model is based on a widely accepted definition of play: "A transaction that occurs between the individual and their environment that is intrinsically motivated, internally controlled, free from the constraints of objective reality and requires skills related to framing (reading and responding to cues) (Bateson, 1971, 1972; Skard & Bundy, 2008); and considered how children's difficulties would impact on their play with peers. The model provides a way of understanding how the child's underlying skills and behavioral elements characteristic of play, and the influence of environmental factors, have on play.

The model of children's play has three components; (1) The child's developmental capacities (Cognitive, physical and social skills) and (2) individual play style (Internal control, freedom to suspend reality and intrinsic motivation) which make up the child's contribution to the play transaction. The third component is the (3) environment and the cultural milieu which influences the child's play.

After reviewing the principles of the model of children's play and the impact of child abuse on children's play, the current researchers felt that the model can be used as a guide for exploring children's play; observable forms and context, in the current research. In applying the model of children's play, we are able to explore how aspects of play itself and environmental factors can be addressed in a play based intervention to promote playfulness in children with HIV/Aids.

For further reading about the play based intervention model, please refer to:

- Cooper, R. J. (2000). The impact of child abuse on children's play: A conceptual model. Occupational Therapy International, 7(4), 259-276.

Note. Please print Table 1 or have a copy open on your computer while you complete the survey as you will need to refer to it regularly.

End of Block: THE PLAY BASED INTERVENTION MODEL

Start of Block: QUESTIONS RELATING TO APPLICATION OF THE PLAY BASED INTERVENTION MODEL IN PROMOTING PLAY IN CHILDREN WITH HIV/AIDS

Based on the information you have been provided, and your experience in HIV/Aids <u>OR</u> play, do you agree that the model of children's play can be applied to children living with HIV/Aids?

- ○ Strongly Agree (1)
- ○ Agree (2)
- ○ Neutral (3)
- ○ Disagree (4)
- ○ Strongly Disagree (5)

Display This Question:
If Based on the information you have been provided, and your experience in play/HIV/Aids or play, do you agree that th... = Strongly Disagree
Or Based on the information you have been provided, and your experience in play/HIV/Aids or play, do you agree that th... = Disagree

If you disagree or strongly disagree, please provide your reasoning here.

_____
_____
_____

Page Break

Please indicate your level of agreement with relationships illustrated in the children's play model as they apply to children with HIV/Aids.

Child's cognitive play skills make a contribution to the play transaction. For example, a child using his/her cognitive skills may be able to transform inanimate objects into toys and use symbolic actions to represent properties or absent objects in symbolic play.

- ○ Strongly Agree (1)
- ○ Agree (2)
- ○ Neutral (3)
- ○ Disagree (4)
- ○ Strongly Disagree (5)

Display This Question:
If Child's cognitive play skills make a contribution to the play transaction. For example, a child... = Disagree
Or Child's cognitive play skills make a contribution to the play transaction. For example, a child... = Strongly Disagree

If you disagree or strongly disagree, please provide your reasoning here.

_____
_____

Child's physical play skills make a contribution to the play transaction. For example, a child who has developed physical skills is likely to engage in play mastering gross motor and fine motor skills.

- ○ Strongly Agree (1)
- ○ Agree (2)
- ○ Neutral (3)
- ○ Disagree (4)
- ○ Strongly Disagree (5)

Display This Question:
If Child's physical play skills make a contribution to the play transaction. For example, a student... = Disagree
Or Child's physical play skills make a contribution to the play transaction. For example, a student... = Strongly Disagree

If you disagree or strongly disagree, please provide your reasoning here.

_____

_____

Child's social play skills make a contribution to the play transaction. For example, a child's proficiency in social skills is underpinned by the ability to communicate with peers.

- ○ Strongly Agree (1)
- ○ Agree (2)
- ○ Neutral (3)
- ○ Disagree (4)
- ○ Strongly Disagree (5)

Display This Question:
If Child's social play skills make a contribution to the play transaction. For example, a student... = Disagree
Or Child's social play skills make a contribution to the play transaction. For example, a student... = Strongly Disagree

If you disagree or strongly disagree, please provide your reasoning here.

_____

_____

_____

Do you think Caregiver involvement should be part of play based interventions?

- ○ Strongly Agree (1)
- ○ Agree (2)
- ○ Neutral (3)
- ○ Disagree (4)
- ○ Strongly Disagree (5)

Display This Question:
If Caregiver involvement should be part of the play based intervention.... = Disagree
Or Caregiver involvement should be part of the play based intervention. ... = Strongly Disagree

If you disagree or strongly disagree, please provide your reasoning here.

_____

_____

Do you think Peer involvement should be part of play based interventions?

- ○ Strongly Agree (1)
- ○ Agree (2)
- ○ Neutral (3)
- ○ Disagree (4)
- ○ Strongly Disagree (5)

Display This Question:
If Peer involvement should be part of the play based intervention.... = Disagree
Or Peer involvement should be part of the play based intervention. ... = Strongly Disagree

If you disagree or strongly disagree, please provide your reasoning here.

_____

_____

Do you think Video Modelling should be part of play based interventions?

- ○ Strongly Agree (1)
- ○ Agree (2)
- ○ Neutral (3)
- ○ Disagree (4)
- ○ Strongly Disagree (5)

Display This Question:
If Video Modelling should be part of the play based intervention.... = Disagree
Or Video Modelling should be part of the play based intervention. ... = Strongly Disagree

If you disagree or strongly disagree, please provide your reasoning here.

_____

_____

Do you think building resilience among children with HIV/Aids should be part of the play based intervention?

- ○ Strongly Agree (1)
- ○ Agree (2)
- ○ Neutral (3)
- ○ Disagree (4)
- ○ Strongly Disagree (5)

Display This Question:
If Building resilience among children with HIV/Aids should be part of the play based intervention.... = Disagree
Or Building resilience among children with HIV/Aids should be part of the play based intervention. ... = Strongly Disagree

If you disagree or strongly disagree, please provide your reasoning here.

_____
_____
_____
_____
_____

Do you think increasing social interaction should be part of play based interventions?

- ○ Strongly Agree (1)
- ○ Agree (2)
- ○ Neutral (3)
- ○ Disagree (4)
- ○ Strongly Disagree (5)

Display This Question:
If increasing social interaction should be part of the play based intervention.... = Disagree
Or increasing social interaction should be part of the play based intervention. ... = Strongly Disagree

If you disagree or strongly disagree, please provide your reasoning here.

_____
_____
_____

Do you think awareness campaigns on the importance of play in the development of children with HIV should be part of play based interventions?

- ○ Strongly Agree (1)
- ○ Agree (2)
- ○ Neutral (3)
- ○ Disagree (4)
- ○ Strongly Disagree (5)

Display This Question:
If awareness campaigns should be part of the play based intervention.... = Disagree
Or awareness campaigns should be part of the play based intervention. ... = Strongly Disagree

If you disagree or strongly disagree, please provide your reasoning here.

_____
_____
_____

Do you think awareness campaigns on dispelling Myths associated with HIV/Aids should be part of play based interventions?

- ○ Strongly Agree (1)
- ○ Agree (2)
- ○ Neutral (3)
- ○ Disagree (4)
- ○ Strongly Disagree (5)

Display This Question:
If dispelling myths should be part of the play based intervention.... = Disagree
Or dispelling myths should be part of the play based intervention. ... = Strongly Disagree

If you disagree or strongly disagree, please provide your reasoning here.

_____

Do you think psychosocial education should be part of play based interventions?

- ○ Strongly Agree (1)
- ○ Agree (2)
- ○ Neutral (3)
- ○ Disagree (4)
- ○ Strongly Disagree (5)

Display This Question:
If psycho-education should be part of the play based intervention.... = Disagree
Or Psycho- education should be part of the play based intervention. ... = Strongly Disagree

If you disagree or strongly disagree, please provide your reasoning here.

_____
_____

(If you reside or have practiced in African countries please answer the following question)
What care the culturally appropriate ways of delivering psychosocial education to caregivers on play do you think should be included in the play based intervention for children with HIV?

- ○ Dance
- ○ Use local language
- ○ Story-telling
- ○ Arts and crafts
- ○ Other

specify_____

Do you think strategies to overcome stigmatization should be part of play based interventions?

- ○ Strongly Agree (1)
- ○ Agree (2)
- ○ Neutral (3)
- ○ Disagree (4)
- ○ Strongly Disagree (5)

Display This Question:
If strategies to overcome stigmatisation should be part of the play based intervention.... = Disagree
Or strategies to overcome stigmatisation should be part of the play based intervention. ... = Strongly Disagree

If you disagree or strongly disagree, please provide your reasoning here.

_____
_____
_____

Do you think cultural sensitive practices about play should be part of play based interventions?

- ○ Strongly Agree (1)
- ○ Agree (2)
- ○ Neutral (3)
- ○ Disagree (4)
- ○ Strongly Disagree (5)

Display This Question:
If cultural sensitive practices about play should be part of the play based intervention.... = Disagree
Or cultural sensitive practices about play should be part of the play based intervention. ... = Strongly Disagree

If you disagree or strongly disagree, please provide your reasoning here.

_____
_____

(If you reside or have practiced in African countries please answer the following question)
What cultural sensitive practices do you think should be included in play based interventions for children with HIV?

- ○ Indigenous/Endogenous Games
- ○ Indigenous/Endogenous songs
- ○ Low cost toys
- ○ Gender balanced toys
- ○ Other

specify_____
_____

Based on your experience in HIV/Aids, and your understanding of the play based intervention model, do you feel there are any constructs that need to be removed, added or changed, when considering play based intervention for children with HIV/Aids?

- ○ Yes (1)
- ○ No (2)

When applying the play based intervention to children with HIV/Aids, do you think compliance to medication should be considered as a separate and additional component?

- ○ Strongly Agree (1)
- ○ Agree (2)
- ○ Neutral (3)
- ○ Disagree (4)
- ○ Strongly Disagree (5)

Display This Question:
If When applying the play based intervention to children with HIV/Aids, compliance to medication should... = Disagree
Or When applying the play based intervention to children with HIV/Aids, compliance to medication should... = Strongly Disagree

If you agree or strongly agree, please describe if and where you think compliance to medication fits into play based intervention to children with HIV/Aids.

_____
_____
_____

If you disagree or strongly disagree, please provide your reasoning here.

_____

When applying the play based intervention to children with HIV/Aids, do you think provision of food should be considered as a separate and additional component? For example, when children attend play based sessions, they should be provided with a healthy snack before or after the intervention. When the children are not hungry, they tend to engage more in play.

- ○ Strongly Agree (1)
- ○ Agree (2)
- ○ Neutral (3)
- ○ Disagree (4)
- ○ Strongly Disagree (5)

Display This Question:
If Provision of food is important to promote playfulness in children with HIV/Aids For example, a student... = Disagree
Or Provision of food is important to promote playfulness in children with HIV/Aids For example, a student... = Strongly Disagree

If you disagree or strongly disagree, please provide your reasoning here.

_____
_____
_____

Display This Question:
If Based on your experience in HIV/Aids, and your understanding of the play based intervention model, do you feel there are any co... = Yes

Please comment on what you feel needs to be removed, added or changed.

_____
_____

Please provide any general comments you may have about children with HIV/Aids, participation and the application of the play based intervention to children with HIV/Aids.

_____
_____
_____

Page Break

Thank-you for taking the time to complete this survey. Your response has been recorded.

You will receive an email in approximately 4 to 6 weeks with a summary of findings from this round of the Delphi, and a link to the second survey.

Your ongoing input is very much appreciated. If you have any questions please contact the primary investigator on email (dngnya002@myuct.ac.za)

If you would like to view the reference list, please click here.

End of Block: QUESTIONS RELATING TO APPLICATION OF CHILDREN'S PLAY MODEL TO PLAY BASED INTERVENTION FOR CHILDREN WITH HIV/Aids

7.22 APPENDIX W: Second Round Delphi Questionnaire

BLOCK ONE – INSTRUCTIONS

Thank-you for participating in the first round of the Delphi study

All completed responses from the first round of the Delphi study were subjected to data analysis using the SPSS version 26 and content analysis was used on all free responses. Summary of the findings from round 1 are attached. Please go through the findings before responding to the second round survey questionnaire. This second round seeks to gain expert consensus on the content and delivery of the play based intervention guidelines for children with HIV/Aids living in low resourced settings.

This survey should take **approximately [30 to 40 minutes] to complete**, however this may vary depending on your responses.

Remember that **you can leave this survey (multiple times) and come back later to where you left off**, if you **use the same computer and same web-browser** (i.e. do not start the survey on your mobile, then switch to a desktop computer) each time. You do not have to click a "save" button, just close the survey window and use the link to open the survey up again later. To ensure your response is recorded, please make sure you reach the very last page of the survey before closing your web browser.

Please make sure you have read "Summary of findings from Round 1" before responding to the questions in this survey. You can click on this link OR open the attachment in the email that was sent to you.

BLOCK TWO – CONFIDENTIALITY

The following survey includes information about a play based intervention that is currently being developed. Information about the play based intervention in this survey is confidential and should not be disclosed in any manner or form, directly or indirectly, to any person or entity under any circumstances.

BLOCK THREE – Questions related to the development of play based intervention

This survey round will be asking questions about the ***content and delivery*** of the play based intervention.

There are many complex factors to consider when working with children living with HIV/Aids using play based intervention. It is impossible for a single intervention to address all of these challenges. Please keep in mind when completing the survey that the intervention developed as a result of this study **focuses on** promoting **play in children with HIV/Aids.**

1. Video-modelling is a form of observational learning in which desired behaviours are learned by watching a video demonstration and then imitating the behaviour of the model. The basis of video modelling comes from the observational social learning theory (Bandura & Walters, 1977) which suggests that most human behaviour is learnt by watching behaviour modelled by other individuals. Video modelling technique can be adapted to the needs of the client as part of a complex intervention programme, or implemented by others, with little instruction and equipment (Prater et al., 2012). In this play based intervention, video modelling will involve the Therapists video filming the children whilst playing and then later watches the play videos with the children, discussing the good and bad behaviours as well as future adjustments. Video technology has the capacity to be easily accessible, especially with the availability of smart phones and tablets. Also, Video use allows for multiple skills to be captured for reflection over time and across settings, extending gains beyond the intervention period and context (Wilkes-Gillan et al., 2014). This may be beneficial for children with HIV/Aids whom from our previous studies showed that they experienced some difficulties in social play skills as compared to typically developing children.

   Do you think video modelling should be part of the play based intervention?

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree

   * If you 'disagree' or 'strongly disagree', please provide your reasoning (force)

   *If you responded 'neutral' please provide your reasoning here (force

2. HIV and AIDS affect most the productive people, leading to reduced capacity to either produce food or generate income. Lack of health food for people with HIV/Aids may lead to a faster progression of Aids related illness. Children are the most vulnerable group in the affected households. The World Health Organization recommends that children with HIV/Aids should increase energy intake and maintain a balanced macronutrient distribution for optimal growth and nutrition. The play based intervention will be held in low resourced settings where availability of food for children may be a challenge. In

children, the impact of lack of health food is likely to be huge and might affect the ability of the child to engage in play based intervention. When the children are not hungry, they tend to engage more in play. Thus we propose that there should be provision of food before or after play session.

When applying the play based intervention to children with HIV/Aids, do you think provision of food should be considered as a separate and additional component? For example, when children attend play based sessions, they should be provided with a healthy snack before or after the intervention.

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree

* If you 'disagree' or 'strongly disagree', please provide your reasoning (force)

*If you responded 'neutral' please provide your reasoning here (force)

3. The advent of antiretroviral medication has resulted in improvements in health and life expectancy of children living with HIV/Aids (Potterton et al., 2016). However, successful antiretroviral therapy is dependent on sustaining high levels of compliance to medication which includes correct dosage, taken on time, and in the correct way. Compliance to treatment is of paramount importance in order to achieve the full efficacy of treatment and also to prevent the incidence of drug resistance. Non compliance causes medical and psychosocial complications of disease, reduces patients' quality of life, and may result in child not engaging in play. Thus, the play based intervention should promote compliance to medication. It should not be viewed as a substitute to existing treatment programs but complimentary. Inorder to carb that confusion, we are of the view that the play based intervention should also incooperate aspects of negotiating time for play whilst being compliant to medication. Play should be accomodated in the child's routine without compromising adherence to medication.

When applying the play based intervention to children with HIV/Aids, do you think compliance to medication should be considered as a separate and additional component?

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree

* If you 'disagree' or 'strongly disagree', please provide your reasoning (force)

*If you responded 'neutral' please provide your reasoning here (force)

[PAGE BREAK]

BLOCK FOUR_ - PLAY BASED INTERVENTION

The model of children's play by Cooper (Cooper, 2000) was used to guide development of this play based intervention. Cooper's Model incorporated Bundy's model and definition of playfulness. Playfulness is defined as "a transaction that occurs between the individual and their environment that is intrinsically motivated, internally controlled, free from the constraints of objective reality and requires skills related to framing (reading and responding to cues) (Skard & Bundy, 2008). In developing the play based intervention, the elements of playfulness (Internal control, intrinsic motivation, freedom to suspend reality and framing will be discussed in relation to children with HIV/Aids.

Internal control refers to the child's ability to determine what happens and how or with whom she or he is playing with (Bundy, 1997). Children with HIV/Aids have difficulties in deciding what to do, modifying tasks, interacting with objects, negotiating needs, playing with others, sharing ideas and objects.

*(Please click on*to get an explanation of the technique is given below)*

1. **Test of Playfulness item: Deciding what to do - the proportion of time during which the player actively chooses to do what she is doing.** *For example a child may just stare at the toys without playing or get stuck on one play theme without changing.*
   When working with children with HIV/Aids, what techniques or approaches or treatment principles do you think will be appropriate for use when addressing difficulties in deciding what to do?

   - Caregiver Education*
   - Therapist Modelling*
   - Peer Modelling*
   - Video Modelling*
   - Decentering*
   - Giving out play resources
   - Make sure the environment is physically and emotionally safe
   - Allow the child to select tasks
   - Players should experience success most times during play
   - Other specify_____

2. **Test of Playfulness item: Interacting with objects - the degree to which the player gets involved with objects. It ranges from the players who simply manipulates objects to the player who actively engages in continuous give-and take interaction with objects.** *For example player may have difficulty in manipulating, exploring objects and this may be due to poor skill or the effort of interacting far exceeds the value of the objects to play.*
   When working with children with HIV/Aids, what techniques do you think will be appropriate for use when the child experiences difficulties with interacting with objects?

   - Caregiver Education*
   - Therapist Modelling*

- Peer Modelling*
- Video Modelling*
- Decentering*
- Giving out play resources
- Make sure the environment is physically and emotionally safe
- Allow the child to select tasks
- Players should experience success most times during play
- Other specify_____

3. **Test of Playfulness item: modifying Task - the ease with which the player actively changes the requirements or complexity of the task in order to vary the challenge or degree of novelty.** *For example a child may simply repeat an activity or the play does not seem to evolve.* **When working with children with HIV/Aids, what techniques do you think will be appropriate for use when addressing difficulties in modifying tasks?**

    - Caregiver Education*
    - Therapist Modelling*
    - Peer Modelling*
    - Video Modelling*
    - Decentering*
    - Giving out play resources
    - Make sure the environment is physically and emotionally safe
    - Allow the child to select tasks
    - Players should experience success most times during play
    - Other specify_____

4. **Test of Playfulness item: negotiates needs with others - the ease and finesse with which the player verbally or nonverbally asks for what she needs or wants.** *(For example a child may just stare at the toys without playing or get stuck on one play theme without changing).* **When working with children with HIV/Aids, what techniques do you think will be appropriate for use when addressing difficulties in negotiating needs with others?**

    - Caregiver Education*
    - Therapist Modelling*
    - Peer Modelling*
    - Video Modelling*
    - Decentering*
    - Giving out play resources
    - Make sure the environment is physically and emotionally safe
    - Allow the child to select tasks
    - Players should experience success most times during play
    - Other specify_____

5. **Test of Playfulness item: supports play of others - the ease with which the player enables others to play and enjoy their play.** *For example a child may be concerned almost entirely with meeting own needs rather than enabling others to play also or is so passive.*
   When working with children with HIV/Aids, what techniques do you think will be appropriate for use when addressing difficulties in supporting play of others?

   - Caregiver Education*
   - Therapist Modelling*
   - Peer Modelling*
   - Video Modelling*
   - Decentering*
   - Giving out play resources
   - Make sure the environment is physically and emotionally safe
   - Allow the child to select tasks
   - Players should experience success most times during play
   - Other specify_____

6. Test of Playfulness item: **skill of sharing objects and ideas - the ease with which the player allows others to use toys, personal belongings, or equipment he is using or shares playmates (friends) or ideas.** *For example a child may refuse to share or seems unaware that she possesses something another would like and allows the other to take it without noticing.*
   When working with children with HIV/Aids; what techniques do you think will be appropriate for use when addressing difficulties in sharing ideas and objects?

   - Caregiver Education*
   - Therapist Modelling*
   - Peer Modelling*
   - Video Modelling*
   - Decentering*
   - Giving out play resources
   - Make sure the environment is physically and emotionally safe
   - Allow the child to select tasks
   - Players should experience success most times during play
   - Other specify_____

Freedom to suspend reality:

Freedom to suspend reality refers to the child's ability to introduce non literal, pretend elements into play (Bundy, 1997). Children with HIV/Aids are likely to experience difficulty in the extent and skill of pretending as well as extend and skill of using people or objects unconventionally.

7. **Test of Playfulness item: Extend of pretending - the proportion of time during which there are overt indicators the player is pretending to be someone she is not (assuming different character roles) pretending to be doing something he is not really doing, pretending**

something is happening that is not, or pretending an object or person is something other than what it actually is. *For example the child might have difficulty in using an object in ways other than its intended purpose.*
When working with children with HIV/Aids; what techniques do you think will be appropriate for use when addressing difficulties in extend of pretending?

- Caregiver Education*
- Therapist Modelling*
- Peer Modelling*
- Video Modelling*
- Decentering*
- Giving out play resources
- Make sure the environment is physically and emotionally safe
- Allow the child to select tasks
- Players should experience success most times during play
- Other specify_____

8. **Test of Playfulness item:** skill of pretending **– the degree to which the performance is convincing to the examiner.** *For example the child cannot assume a role like being a teacher or doctor in a convincing way.*
When working with children with HIV/Aids; what techniques do you think will be appropriate for use when addressing difficulties in skill of pretending?

- Caregiver Education*
- Therapist Modelling*
- Peer Modelling*
- Video Modelling*
- Decentering*
- Giving out play resources
- Make sure the environment is physically and emotionally safe
- Allow the child to select tasks
- Players should experience success most times during play
- Other specify_____

9. **Test of Playfulness item: extend of using people or objects unconventionally - the proportion of time during which the player sees the possibilities within a toy, object, or person and acts on those possibilities in clever or creative ways.** *(For example, she may not or rarely express objects commonly thought of as toys in ways other than those the manufacturer clearly intended or incorporate objects not classically thought of as toys into the play (e.g., bugs, table legs).*

When working with children with HIV/Aids; what techniques do you think will be appropriate for use when addressing difficulties in extend of using people or objects unconventionally?

- Caregiver Education*
- Therapist Modelling*
- Peer Modelling*
- Video Modelling*
- Decentering*
- Giving out play resources
- Make sure the environment is physically and emotionally safe
- Allow the child to select tasks
- Players should experience success most times during play
- Other specify_____

10. **Test of Playfulness item: skill of using people or objects unconventionally - the ease with which the player incorporates objects or other people in creative ways.** *(For example child may have difficulty in incorporates objects or other people in creative ways).*

When working with children with HIV/Aids; what techniques do you think will be appropriate for use when addressing difficulties in skill of using people or objects unconventionally?

- Caregiver Education*
- Therapist Modelling*
- Peer Modelling*
- Video Modelling*
- Decentering*
- Giving out play resources
- Make sure the environment is physically and emotionally safe
- Allow the child to select tasks
- Players should experience success most times during play
- Other specify_____

Intrinsic motivation

Intrinsic motivation refers to a child's willingness to engage in play activities or with playmates (Cooper, 2000). Although children with HIV/Aids showed willingness to play, they are likely to express lower intensity of persistence in play, hence are likely to give up easily on a play task.

11. **Test of Playfulness item: intensity of persistence in play - the degree to which the player perseveres in order to overcome obstacles to continuing the activity. (***For example when a child does not try hard or persevere in order to overcome obstacles to continuing the activity).*
When working with children with HIV/Aids; what techniques do you think will be appropriate for use when a child expresses express lower intensity of persistence in play?

- Caregiver Education*
- Therapist Modelling*
- Peer Modelling*
- Video Modelling*
- Decentering*
- Giving out play resources
- Make sure the environment is physically and emotionally safe
- Allow the child to select tasks
- Players should experience success most times during play
- Other specify_____

Framing

Framing refers to the ability to appropriately give and read play cues from the environment and other playmates (Pearton et al., 2014). Children with HIV/Aids are likely to experience difficulties in giving and responding to cues as well as poor skills of being engaged in play.

12. **Test of Playfulness item: giving Cues - the proportion of time during which the player acts in such a way as to give out clear messages about how others should interact with her. This includes both nonverbal and verbal cues.** *For example a child with HIV/Aids may express difficulty in giving clear verbal and/or nonverbal cues during play.*
    When working with children with HIV/Aids; what techniques do you think will be appropriate for use when addressing difficulties in giving cues?

    - Caregiver Education*
    - Therapist Modelling*
    - Peer Modelling*
    - Video Modelling*
    - Decentering*
    - Giving out play resources
    - Make sure the environment is physically and emotionally safe
    - Allow the child to select tasks
    - Players should experience success most times during play
    - Other specify_____

13. **Test of Playfulness item: responding to Cues - the ease with which the player acts in accord with others' play cues.** *(For example a child has difficulty in understanding and acting on the cues given by playmates during play).*
    When working with children with HIV/Aids; what techniques do you think will be appropriate for use when addressing difficulties in responding to cues?

    - Caregiver Education*
    - Therapist Modelling*
    - Peer Modelling*

- Video Modelling*
- Decentering*
- Giving out play resources
- Make sure the environment is physically and emotionally safe
- Allow the child to select tasks
- Players should experience success most times during play
- Other specify_____

14. **Test of Playfulness item: skill of being engaged - the player maintains single, or multiple clearly connected, play themes during the time the player is engaged in play.** *(for example a child might stop playing express on looker behaviours during play)*
    When working with children with HIV/Aids; what techniques do you think will be appropriate for use when addressing difficulties in engaging in play?

    - Caregiver Education*
    - Therapist Modelling*
    - Peer Modelling*
    - Video Modelling*
    - Decentering*
    - Giving out play resources
    - Make sure the environment is physically and emotionally safe
    - Allow the child to select tasks
    - Players should experience success most times during play
    - Other specify_____

[PAGE BREAK]

BLOCK 5: PRE-INTERVENTION LEARNING FOR CAREGIVERS

Based on participant comments from the first round, it is proposed that the play based intervention will include pre-intervention learning for caregivers of children with HIV/Aids. This section will ask for your expert opinion on some of the proposed topics that have been identified as potential content areas for pre-intervention caregiver learning

15. How important do you think that '**Play in children – (characteristics of play, play things and toys, benefits of play, positive outcomes and long term implications)'** should be included as a topic in the pre intervention learning for caregivers

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree

* If you 'disagree' or 'strongly disagree', please provide your reasoning (force)

*If you responded 'neutral' please provide your reasoning here (force)

16. How important do you think that **'HIV/Aids – (characteristics, misunderstandings and myths, common challenges in play'** should be included as a topic in the pre intervention learning for caregivers?

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree

* If you 'disagree' or 'strongly disagree', please provide your reasoning (force)

*If you responded 'neutral' please provide your reasoning here (force)

17. How important do you think that **'Ways/approaches to promote play children with HIV/Aids'** should be included as a topic in the pre intervention learning for caregivers

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree

* If you 'disagree' or 'strongly disagree', please provide your reasoning (force)

*If you responded 'neutral' please provide your reasoning here (force)

18. How important do you think that **'Importance of building positive relationships between home, clinic and school in ways that foster collaborative partnerships'** should be included as a topic in the pre intervention learning for caregivers
    - .

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree

* If you 'disagree' or 'strongly disagree', please provide your reasoning (force)

*If you responded 'neutral' please provide your reasoning here (force)

19. How important do you think that **'Play programs and strategies to assist in individualising play programs to the needs of individual children with HIV/Aids'** should be included as a topic in the pre intervention learning for caregivers?

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree

* If you 'disagree' or 'strongly disagree', please provide your reasoning (force)

*If you responded 'neutral' please provide your reasoning here (force)

20. How important do you think that '**Implementation of the play based intervention – (i.e. how to incorporate into existing play routine, practicing intervention principles, troubleshooting potential challenges'** should be included as a topic in the pre intervention learning for caregivers

Strongly disagree	Disagree	Neutral	Agree	Strongly Agree

* If you 'disagree' or 'strongly disagree', please provide your reasoning (force)

*If you responded 'neutral' please provide your reasoning here (force)

Please provide any feedback you have about the proposed learning content, including any content you think should be removed, added or changed (force).

_____
_____
_____

21. **To maximise the *effectiveness* and the *feasibility* of the intervention, it is important to make sure the frequency, intensity and duration of the pre-intervention caregiver learning is appropriate.**

    a. **In total, <u>how much time per session</u> do you think the caregiver learning should take?**

        - Less than 15minutes
        - 15 minutes to 30minutes
        - 30minutes to 45 minutes
        - 45 minutes to 1 hour
        - Other specify_____

    *Please indicate how much time (in total) you think the professional learning should take (0, forced)

    b. **Over <u>how many sessions</u> do you think the pre-intervention learning should be delivered?**

        - 1-2 sessions
        - 3-4 sessions
        - 5-6sessions
        - 7-8 sessions
        - Other please specify_____

    *** Please specify the number of sessions you think the pre-intervention learning should be delivered over (0, forced)**

c. **In what format do you think the caregiver learning should be delivered?** (multiple choice, select all that apply, forced)

- Written information
- Online
- Face to face
- Power-point / lecture style
- Workshop style
- Other, please specify (forced text)

d. **Please provide any comments you have about the frequency, intensity, duration and/or delivery of the pre-intervention caregiver learning (optional).**

_____
_____
_____

Structure of the intervention

To maximise the effectiveness and the feasibility of the intervention, it is important to make sure the frequency, intensity and duration of the pre-intervention professional learning is appropriate.

22. In total, how much time do you think each session should last?

- 0-30mins
- 30- 60minutes
- 1 hour to 1hour 30 minutes
- 1hour 30minutes to 2hours
- Other specify_____

23. Over how many sessions do you think the play based intervention should be delivered?

6 sessions half a school term
12 sessions Full school term
18 sessions (One and a half school term)
24 sessions (two school terms)
Other specify_____

24. **In what format do you think the caregiver learning should be delivered?** (multiple choice, select all that apply, forced)

- Written information
- Online
- Face to face
- Power-point / lecture style
- Workshop style

Other, please specify (forced text)_____

25. Please provide any comments you have about the frequency, intensity, duration and/or delivery of the pre-intervention professional learning (optional).

_____
_____
_____
_____