

---

# **The one and the many: improving the mental wellbeing of caregivers of children with disabilities in urban Uganda: a cluster randomized controlled trial**

**Namasaba Mariam**  
**Ph.D. student**  
**The University of Tokyo**  
**Graduate School of Medicine**  
**Department of Community and Global Health**

# Overview

## Major sections of this presentation

Introduction

---

Problem statement : Ugandan  
context

---

Rationale

---

Conceptual framework

---

Objective

---

Research question

---

Methodology

Intervention

---

Analysis

---

Results

---

Discussion

---

Conclusion

---

Study limitation

---

Thank you!

# Introduction

## The Health of Primary Caregivers of Children With Cerebral Palsy: How Does It Compare With That of Other Canadian Caregivers?

Jamie C. Brehaut, PhD\*†; Dafna E. Kohen, PhD§||; Parminder Raina, PhD¶||; Stephen D. Walter, PhD¶||; Dianne J. Russell, MSc¶||††; Marilyn Swinton, BSc††; Maureen O'Donnell, MD, FRCP(C)§§; and Peter Rosenbaum, MD\*\*††|||

Minichil et al. BMC Psychiatry (2019) 19:249  
https://doi.org/10.1186/s12888-019-2228-y

BMC Psychiatry

**ABSTRACT.** *Background.* Caring for any child involves considerable resources, but the demands for these resources are often increased when caring for a child with a disability. These demands have implications for the psychologic and physical health of the caregiver (CG). Although a number of recent trends in health care stress the importance of studying and promoting the health of CGs of children with disabilities, the literature in this area exhibits 2 major weaknesses, ie, most studies draw conclusions from relatively small, potentially biased, clinic-based samples and the majority of work has focused on the psychologic health of CGs, whereas little research has been undertaken to study their physical well-being. The goal of this study was to compare the

### RESEARCH ARTICLE

Open Access

## Depression and associated factors among primary caregivers of children and adolescents with mental illness in Addis Ababa, Ethiopia

Woredaw Minichil<sup>1\*</sup>, Wondale Getinet<sup>1</sup>, Habtamu Derajew<sup>2</sup> and Sofia Seid<sup>2</sup>

### Abstract

**Background:** Mental illnesses among children and adolescents are under-recognized and under-treated problems. Depression is one of today's all-too-silent health crises in caregivers. Although primary caregivers of children and adolescents with mental illness are more frequently depressed, little attention is being given to the problem in Ethiopia. Thus, this study aimed to assess prevalence of depression and associated factors among primary caregivers of children and adolescents with mental illness in Ethiopia.

**Methods:** Institution-based cross-sectional study was conducted among primary caregivers of children and adolescents with mental illness in Ethiopia. Systematic random sampling was used to recruit a total of 416 study participants. Patient Health Questionnaire-9 was used to measure depression. After descriptive statistics was conducted, binary logistic regression was employed to carry out bivariate and multivariate analysis.

**Result:** The overall prevalence of depression was 57.6% with 95% CI (53, 62.7). The prevalence of depression among female primary caregivers was 64.6% (n = 181). Female sex (AOR = 2.4, 95% CI: 1.18,4.89), duration of care > 5 years (AOR = 4.2, 95% CI: 2.02,8.70), absence of other caregiver (AOR = 2.7, 95% CI: 1.41,5.34), being mother (AOR = 3.9, 95% CI: 1.90,8.04), autistic spectrum disorder (ASD) (AOR = 4.7, 95% CI: 2.06,10.54) and attention deficit /hyperactivity disorder (ADHD) (AOR = 5.3, 95% CI: 2.14,13.23) diagnosis of children and adolescents and poor social support (AOR = 5.5, 95% CI: 2.04,15.02) were associated with depression.

**Conclusion:** The prevalence of depression among primary caregivers of children and adolescents with mental

## Psychological well-being of caregivers of children with intellectual disabilities: Using parental stress as a mediating factor

J. M. Cramm and A. P. Nieboer  
Erasmus University Rotterdam, The Netherlands

### Abstract

Parental stress has been identified as a major affecter of caregivers' psychological well-being and a risk increaser for unwillingly placing children with disabilities in the care of others. Recognition of effective means to ease caregiving burdens must guide policymaking and will help to provide better and tailored support and intervention for the children. This study aims to characterize caregivers of children with intellectual disabilities who are about to seek outside support and care and to identify the conditions under which psychological well-being and parental stress are affected using parental stress as a mediating factor. We found that parental stress and the child's depressive feelings strongly affected psychological well-being. We also found an indirect relation of restricted caregiver social activities through parental stress. To protect psychological well-being of caregivers, support services should address depressive feelings among children with intellectual disabilities, facilitate caregivers' social activity, and reduce stress.

### RESEARCH ARTICLE

Open Access

## Prevalence of psychological distress among parents of children with intellectual disabilities in Malawi

Charles Masulani-Mwale<sup>1\*</sup>, Felix Kauye<sup>2</sup>, Melissa Gladstone<sup>3</sup> and Don Mathanga<sup>2</sup>

### Abstract

**Background:** Children with intellectual disabilities are common and are increasing in number as more children survive globally. In stark contrast to the 1–3% prevalence of intellectual disability in children globally (reported by WHO), studies from Malawi provide alarmingly high rates (26%). We know that the prevalence of psychological distress is as high as 50% in parents of children with intellectual disabilities in Europe and the US. No such studies have yet been conducted in Africa. This study is aimed at determining the prevalence and risk factors for psychological distress among parents of intellectually disabled children in Malawi.

**Methods:** This quantitative cross-sectional study was conducted in January and February 2015. One hundred and seventy mothers and fathers of children with intellectual disabilities as diagnosed by psychiatric clinical officers were randomly sampled from two selected child disability clinics. The Self-Reporting Questionnaire (SRQ) was used "as measure for psychological distress and questions on socio-demographic variables were administered to all consenting participants." Data was coded, cleaned and analyzed using STATA.

**Results:** 70/170 (41.2%) of parents of children with intellectual disabilities reported psychological distress. Univariate and multivariate analysis showed that area of residence (P < 0.05), low socio-economic status (P < 0.05), knowledge of the disability of one's child (P < 0.05), low confidence in managing the disabled child (P < 0.05), increased perceived burden of care (P = 0.05), and having no sources for psychological support (P < 0.05) significantly predicted psychological distress among the parents for children with disabilities.

**Conclusion:** There is huge burden of psychological distress among parents of intellectually disabled children in



# 88% of caregivers of children with disabilities in Uganda

find it difficult to meet the basic needs of their children and families  
(The African report on children with disabilities 2014)

## Problem

RESEARCH

Open Access



### The role of the household in the social inclusion of children with special needs in Uganda – a photovoice study

Caroline Masquillier<sup>1\*</sup>, Sara De Bruyn<sup>1</sup> and David Musoke<sup>2</sup>

Abstract

**Background:** Social inclusion establishes a basis for the overall wellbeing of children with special needs. Although children's lives are centred around the household, little is known about the household's influence on social inclusion. Therefore, the aim is to investigate the household's role in the social inclusion of children with special needs in Uganda.

**Methods:** Twelve carers of children with special needs participated in this photovoice study on the outskirts of Kampala, Uganda – including a training workshop, home visits, in-depth individual interviews and focus group discussion.

**Results:** The social inclusion of children with special needs is highly complex because it has the potential to both benefit and cause harm. The results show that when a disability is socially devalued to a certain degree, carers and their household members have to deal with the ongoing process of stigma management. Depending on the characteristics of the child, carer and household, this can lead to an upward spiral towards visibility or a downward spiral towards concealment – reinforcing social inclusion or stigma, respectively.

**Conclusions:** Despite the fact that there is disability among Ugandan children it remains a 'hidden reality'. This research helps to reveal this hidden reality by understanding the role of the household in social inclusion in a stigmatized context.

**Keywords:** Social Inclusion, Children with Special Needs, Household, Photovoice Study, Uganda

S. Hartley,\* P. Ojwang,† A. Baguwemu,‡ M. Ddamulira‡ and A. Chavuta§

\*The Centre of International Child Health, Institute of Child Health, London University, London, UK,

†The Uganda National Institute of Special Education (UNISE), Kyambogo University, Kampala, Uganda,

‡Disability Resource Centre, The Uganda National Institute of Special Education (UNISE), Kyambogo University, Kampala, Uganda, and

§Montfort College of Special Needs Education, Blantyre, Malawi

Accepted for publication 18 June 2004

Abstract

**Background** Community-based rehabilitation (CBR) was recommended by the World Health Organization in 1989 as the strategy for improving the quality of life of disabled people and their families, which should be built on local knowledge and practices. In Uganda, there is no documentation on how services relate to local knowledge. There is a need for increased knowledge and understanding of how family members cope with their disabled children to provide the basis for future service development.

**Methods** A qualitative phenomenological design was used to develop an in-depth understanding of how Ugandan families cope with their disabled children in their own communities. Data were collected from 52 families with children with disabilities from five impairment groups, through interviews and observations in three districts of Uganda, one urban, two rural.

**Results** There are many children with disabilities who are included, loved and cared for by their families. A lot of time and money is spent on seeking a cure. The extended family systems are breaking down and the main burden of caring for a disabled family member generally falls on one, sometimes two, female carers. Male members act as gatekeepers, controlling the key decisions concerning the child and the associated resources.

**Conclusions** CBR should move the focus of their services away from the disabled individual towards the whole family. It is important to provide accurate information about causes and prevention of impairments, the realities of a cure, support and respite for the female carers, and opportunities for the involvement of fathers. This methodology is a practical mechanism for collecting data that have the potential to positively influence and guide the development of CBR practice in the locality. At a conceptual level the data support the philosophy of inclusion, social integration, the importance of trust and respect, and utilizing a holistic approach. These are eminently transferable to other settings.

**Keywords**  
coping strategies, Africa, disability, child, qualitative methods, CBR

RESEARCH

Open Access



### The role of the household in the social inclusion of children with special needs in Uganda – a photovoice study

Caroline Masquillier<sup>1\*</sup>, Sara De Bruyn<sup>1</sup> and David Musoke<sup>2</sup>

Abstract

**Background:** Social inclusion establishes a basis for the overall wellbeing of children with special needs. Although children's lives are centred around the household, little is known about the household's influence on social inclusion. Therefore, the aim is to investigate the household's role in the social inclusion of children with special needs in Uganda.

**Methods:** Twelve carers of children with special needs participated in this photovoice study on the outskirts of Kampala, Uganda – including a training workshop, home visits, in-depth individual interviews and focus group discussion.

**Results:** The social inclusion of children with special needs is highly complex because it has the potential to both benefit and cause harm. The results show that when a disability is socially devalued to a certain degree, carers and their household members have to deal with the ongoing process of stigma management. Depending on the characteristics of the child, carer and household, this can lead to an upward spiral towards visibility or a downward spiral towards concealment – reinforcing social inclusion or stigma, respectively.

**Conclusions:** Despite the fact that there is disability among Ugandan children it remains a 'hidden reality'. This research helps to reveal this hidden reality by understanding the role of the household in social inclusion in a stigmatized context.



# What do we know?

---

## Resilience is a mediator of mental wellbeing

- Adaptive coping skills reduce psychological distress  
(Coleman et.al., 1998; Jones & Prinz, 2005)
  - Caregivers with a high sense of self-efficacy have better mental health than counterparts with a low sense of self-efficacy  
(Carter et.al., 2009)
- 

## Cognitive behavioural therapy is effective at improving resilience outcomes

A moderate positive effect with some evidence of mixed interventions having greater benefits  
(Joyce S et.al., 2017)

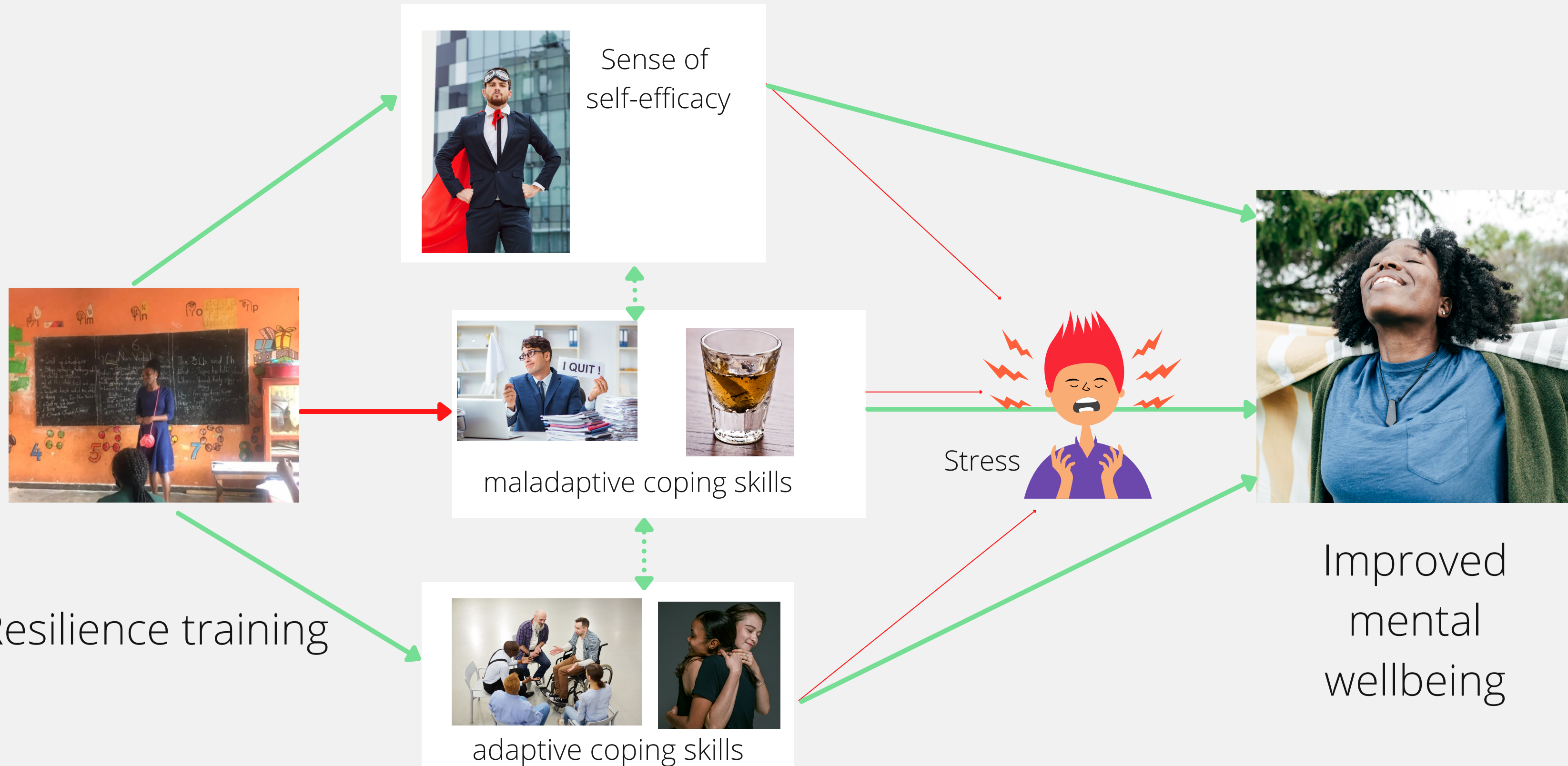
# What is missing?

---

## What type of therapy is suitable for specific groups?

- Group-based therapy?  
(Graziano F, 2013; Rudy BM et.al., 2017)
  - Peer-mentoring?  
(Ramirez A, 2020; Pettit JW et.al., 2017)
-

# Conceptual Framework



# Objective

## Objective

Examine the effect of resilience training on the mental wellbeing of caregivers of children with disabilities in Uganda

---

## Question

Is there an improvement in the mental well-being of caregivers who participate in the resilience workshops compared to caregivers who do not?



# Methodology

## Where is Uganda?



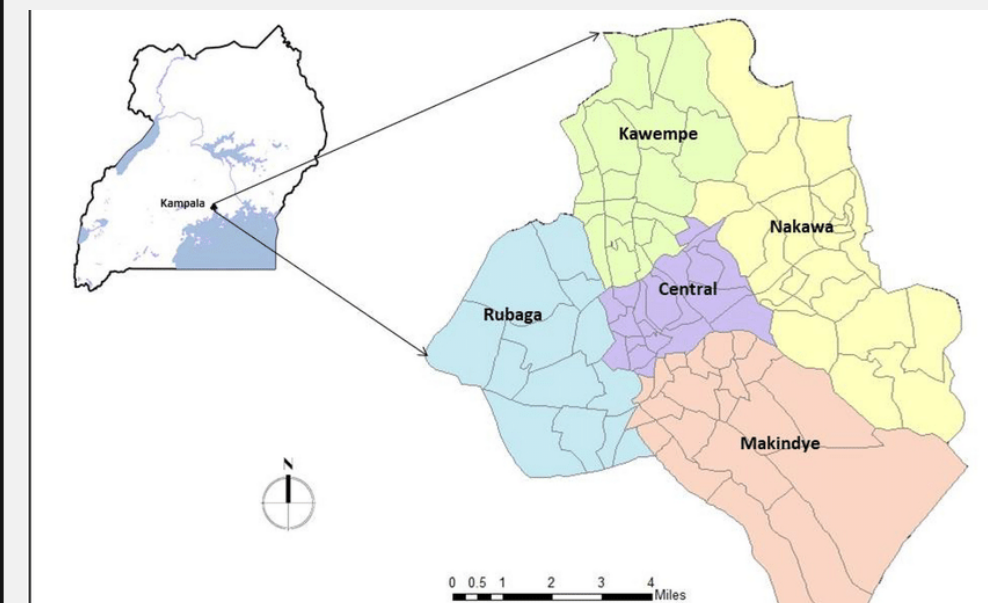
## Study design

- Cluster randomized controlled trial
- Two- parallel arms
- Treatment as usual
- Two-stages of intervention

## Sample size and participants

Estimated sample size:

- home caregivers: 272
- school caregivers: 169



# Intervention

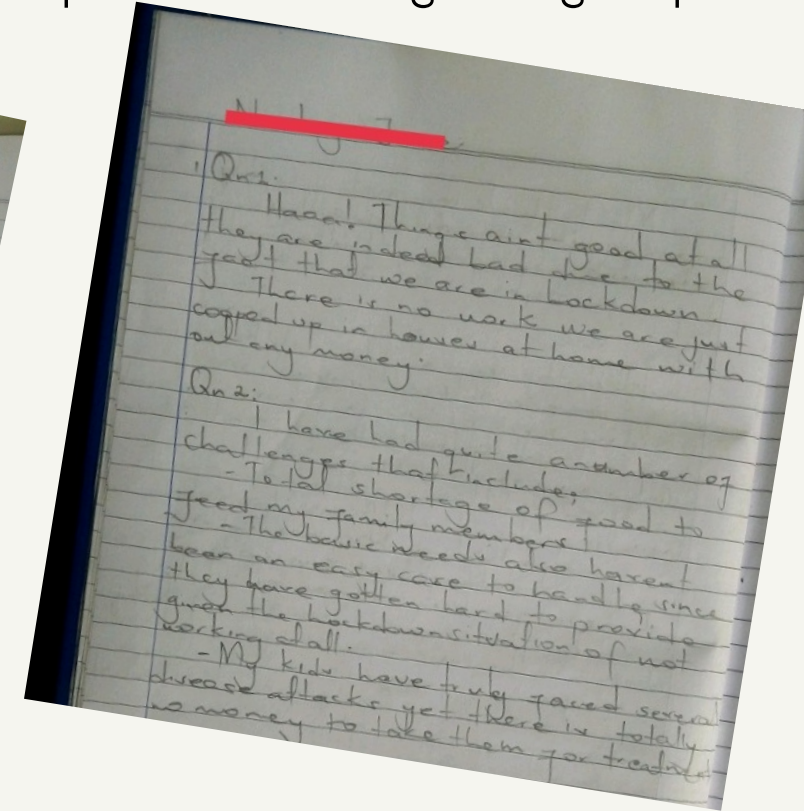
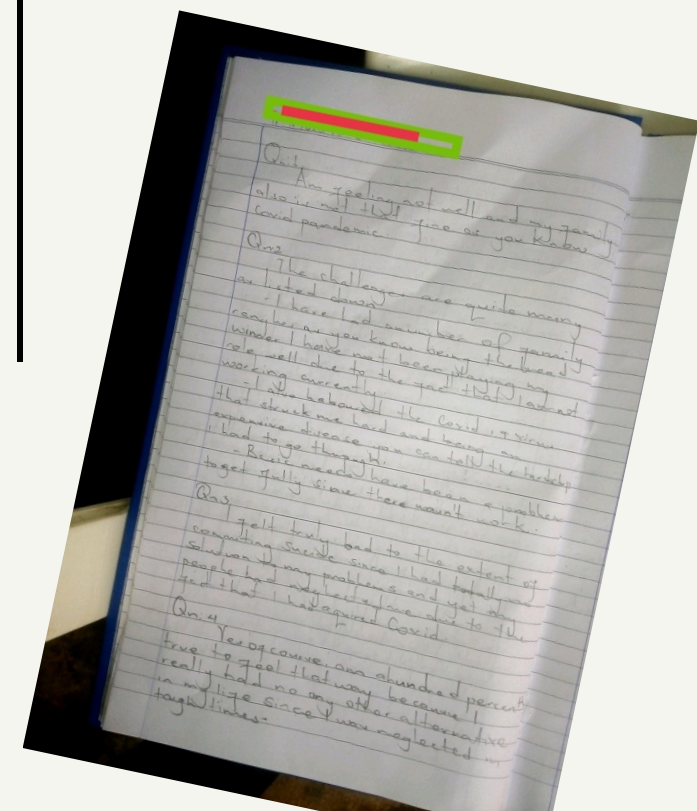
## STAGE 1

- Separate group training for home caregivers and school caregivers
- Delivered by one clinical psychiatric officer and one occupational therapist



## STAGE 2

Phone-based peer mentoring and group discussions



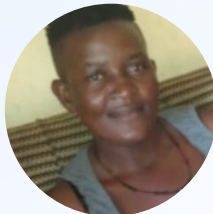



# Results of the Study

---





Table 1: Sociodemographic characteristics of caregivers by allocation arm

Variable

Variable		Description	Control group n (%) 166	Intervention group n (%) 226	Total n(%) 392	P-value
	Caregivers' age	Mean (SD)	40.1 (10.9)	41.0(10.8)	NA	<0.001
	Religion	<ul style="list-style-type: none"><li>• Protestant</li><li>• Catholic</li><li>• Muslim</li><li>• Pentocostal</li></ul>	<ul style="list-style-type: none"><li>• 67 (40.3)</li><li>• 39 (23.5)</li><li>• 26 (15.67)</li><li>• 34(20.5)</li></ul>	<ul style="list-style-type: none"><li>• 87 (38.5)</li><li>• 65 (28.8)</li><li>• 46 (20.35)</li><li>• 28 (12.4)</li></ul>	<ul style="list-style-type: none"><li>• 154 (39.3)</li><li>• 104 (26.5)</li><li>• 72 (18.4)</li><li>• 62 (15.8)</li></ul>	0.13
	Children's age	<ul style="list-style-type: none"><li>• 6-13 years</li><li>• 14-15 years</li><li>• 16-18 years</li></ul>	<ul style="list-style-type: none"><li>• 84 (21.43)</li><li>• 43 (10.9)</li><li>• 30 (7.65)</li></ul>	<ul style="list-style-type: none"><li>• 1566 (39.8)</li><li>• 47 (12.0)</li><li>• 32 (0.82)</li></ul>	<ul style="list-style-type: none"><li>• 240 (61.2)</li><li>• 90 (22.9)</li><li>• 62 (8.5)</li></ul>	<0.001
	Type of disability	<ul style="list-style-type: none"><li>• Intellectual</li><li>• Physical</li><li>• Multiple</li></ul>	<ul style="list-style-type: none"><li>• 37 (9.4)</li><li>• 117 (29.8)</li><li>• 12 (3.1)</li></ul>	<ul style="list-style-type: none"><li>• 66 (16.8)</li><li>• 120 (30.6)</li><li>• 40 (10.2)</li></ul>	<ul style="list-style-type: none"><li>• 103 (26.2)</li><li>• 237 (60.4)</li><li>• 52 (13.3)</li></ul>	0.005

# Effect of the intervention on caregivers' mental wellbeing



		Control group home caregivers	Intervention group home caregivers	Control group school caregivers	Intervention group school caregivers	Comment
	Group-based training	reference	B = -1.29, 95 % CI = -4.52 to 1.93 P = 0.432	reference group	B = 3.98, 95 % CI = 0.178 to 8.85 P = 0.03	Group-based training effectively improved mental wellbeing for school caregivers
	Peer-mentoring	reference group	B = 4.94, 95% CI = 1.73 to 8.15 P = 0.003	reference group	B = -1.60, 95 % CI = -154 to 4.75 P = 0.318	Peer-mentoring effectively improved mental wellbeing for home caregivers



# Discussion

- School caregivers had pre-existing relationships which are important for building social cohesion and improving mental wellbeing (Josendal et.al., 2005).
- Peers provided each other with emotional support which is important for improving mental wellbeing (Lecavalier et.al., 2006).

**Recommendation:** Group-setting may be effective for improving mental wellbeing in workplaces while peer-to-peer support groups may be important effective for improving mental wellbeing in families.

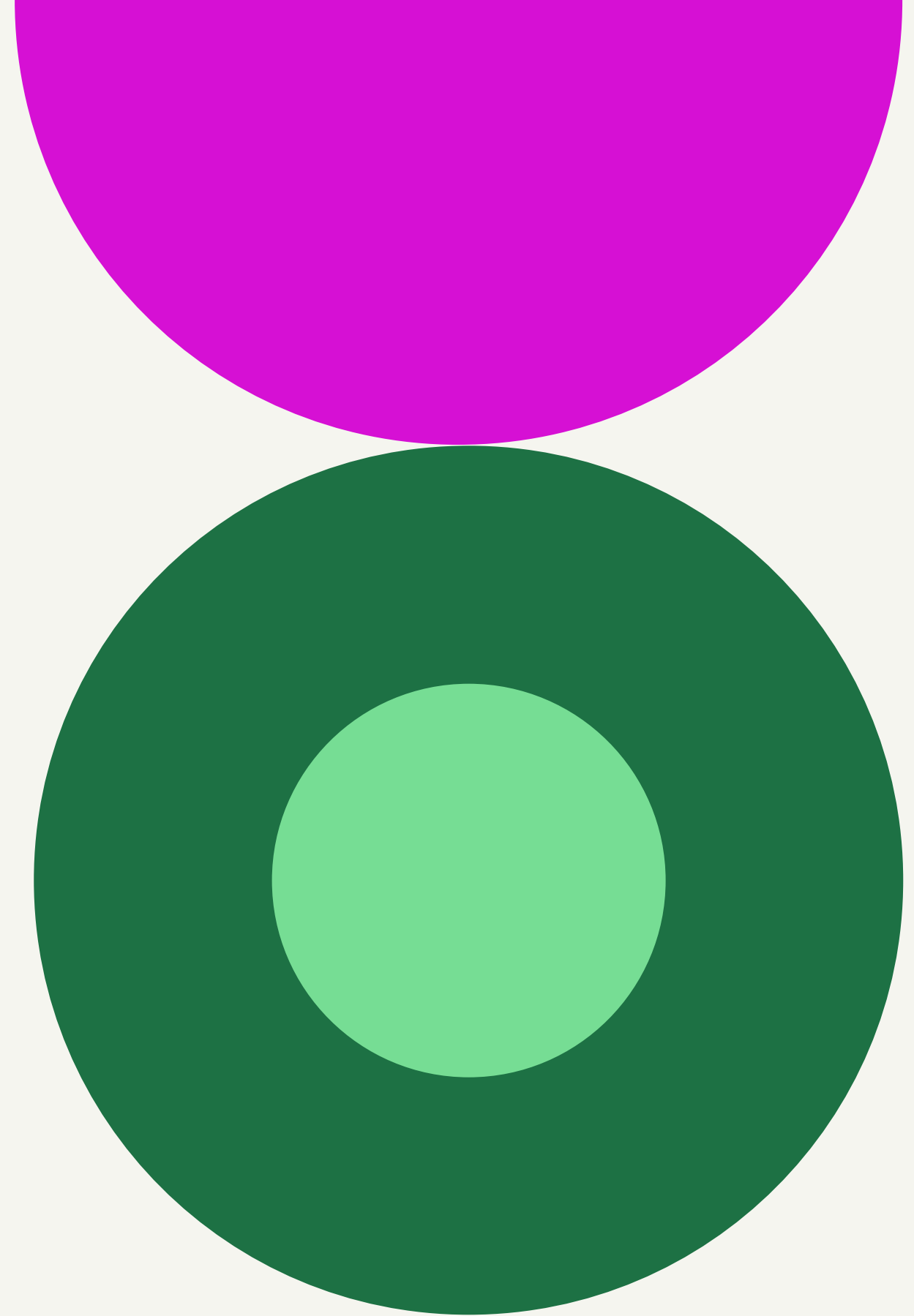




# Study Limitation

## METHODOLOGICAL LIMITATIONS

- Low study power
- Un-perfect randomization
- Self-report assessments
- Contamination between groups





*Thank You*