

**An mHealth communication framework for caregivers of  
adolescents with mental health issues**

**By**

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Doctoral degree in Nursing  
in the School of Nursing  
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at the University of the Free State***

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***PROMOTOR: Dr Marianne Reid***



## DECLARATION

I, Ronelle Jansen, declare that the thesis (interrelated published and publishable articles) that I hereby submit for the Doctoral degree in Nursing at the University of the Free State, is my independent work, and that I have not previously submitted it for a qualification at another institution of higher education.

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**JUNE 2020**

## FINANCIAL CONTRIBUTION

The researcher gratefully acknowledges funding by the Free State Department of Health [DOH 81/16/17] in support of this study. Without this assistance, the research would not have been possible.

# LANGUAGE EDITING CERTIFICATE

## Declaration

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**DEDICATION**

This work is dedicated  
to caregivers of  
teenagers

“So now faith, hope, and love  
abide, these three; but the  
greatest of these is love.”

1 Corinthians 13:13

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## SUMMARY

This study focused on developing an mHealth communication framework for rural caregivers of adolescents with mental health issues. Adolescents carry a high burden of mental health issues. Their caregivers, usually parents, relatives or community members, play a pivotal role in caring for these adolescents, which causes challenges for the caregivers. Caregivers in rural settings face specific challenges relating to adolescents with mental health issues, leading to unmet support needs. The potential value of using communication technology to support rural caregivers has been recognised by research. The aim of the study was to develop an mHealth communication framework for caregivers of adolescents with mental health issues in the Kopanong municipality of the Free State province of South Africa.

This study is best conceptualised as the developmental phase of a complex intervention. A pragmatic study was undertaken by employing a multiple method design and harnessing a three-phase approach that was guided by the theory-of-change logic model, while the integrated model of behaviour prediction (IMBP) served as a conceptualisation of the programme that targeted rural caregivers. Phase 1 implemented a visual-based narrative inquiry that collected data through the Mmogo-method<sup>®</sup>, and aimed to explore caregivers' interest in using communication technology in two towns of the Kopanong municipality in the Free State province of South Africa. The researcher collected data from rural caregivers (n=17) comprising three groups in the towns of Springfontein and Trompsburg. Through a stepwise literature-based process for investigating textual and visual data, the researcher identified four themes. Three themes represent challenges facing caregivers, namely, psychosocial, social resources and informational challenges. Interest in communication technology was the fourth theme. Caregivers favoured using SMS (short messaging service), phone calls and computers.

In Phase 2, literature was reviewed systematically to find the best evidence available to strengthen positive behaviour by caregivers of adolescents with mental health issues by using communication technology interventions. Five articles out of an initial 1 746 articles met the eligibility criteria and were included in the data synthesis. The researcher derived three thematic conclusions: 1) The target population included

parents and family members serving as caregivers; 2) Caregivers experienced improved IMBP determinants (self-efficacy, knowledge, parent/child communication, parental skills), which was reflected in positive behaviour; and 3) Caregivers used various types of communication technologies (SMS, emails, phone calls, online communication, social media).

Findings from these two phases were triangulated to develop a draft framework based on the theory-of-change logic model components. The completed draft framework was presented to expert stakeholders in the third phase during a workshop. Phase 3 comprised a one-day validation workshop that was attended by nine expert stakeholders involved in various adolescent healthcare settings. An experienced facilitator coordinated the workshop, thereby enabling a discussion on each component suggested in the theory-of-change logic model, using forward and backward mapping. Expert stakeholders contributed to three theory-of-change components depicted in the framework, specifically, community needs, desired results, and evidence-based strategies, to finalise the framework. This validation workshop concluded after consensus was reached on the final framework.

Through evidence-based research, the framework can facilitate a programme for supporting caregivers through an mHealth initiative that results in positive caregiver behaviour change. This framework for an mHealth initiative for rural caregivers of adolescents with mental health issues illustrates the development phase of a complex intervention. Piloting this framework will be the next phase. The researcher will participate in the piloting, with the Free State Department of Health being a key stakeholder.

### **Keywords**

Caregiver, adolescent, mental health issues, rural, communication technology, mHealth, theory-of-change logic model, integrated model of behaviour prediction, framework

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## LIST OF ABBREVIATIONS AND ACRONYMS

AIDS	Acquired immune deficiency syndrome
DALY	Disability-adjusted life year
DSM	Diagnostic and Statistical Manual
DHMIS	District Health Management Information Systems
eHealth	Electronic health
HIV	Human immunodeficiency virus
ICT	Information communication technology
IMBP	Integrated model of behaviour prediction
IVR	Interactive voice response
LMIC	Low and middle-income country
mHealth	Mobile Health
MMS	Multimedia services
PHC	Primary healthcare
PICO	Population, intervention, comparison intervention, outcome
SMS	Short messaging service
WHO	World Health Organization

## **PREAMBLE**

The layout of this thesis complies with the recommendations for a PhD through interrelated publishable articles, as presented within the Faculty of Health Sciences of the University of the Free State, South Africa. This thesis comprises interrelated publishable or published articles, in conjunction with introductory and concluding chapters, as opposed to the traditional format.

This thesis has seven chapters. The first chapter presents an overview of the study, its aim, research questions, and methodologies. The second chapter introduces literature related to caregivers of adolescents with mental health issues, while the third chapter presents literature associated with mobile health communication and the caregiver. Chapter 4 presents a published article on the interest of rural caregivers of adolescents with mental health issues in using communication technology. Chapter 5 follows with a published article reporting a systematic review on caregivers of adolescents with mental health issues using communication technology. Chapter 6 describes the development process of a framework for an mHealth initiative to support rural caregivers of adolescents with mental health issues in a manuscript that is under review. Chapters 4 to 6 are interrelated, with each addressing one of the three objectives of the study. Chapter 7 presents conclusions, implications, and limitations of the study. Repetitive issues and concepts may be detected throughout this thesis due to interlinkages between articles contributing to the development of the framework.

The researcher was responsible for developing and writing articles presented in Chapters 4 to 6. Each article indicates the respective contributions of the researcher and co-author. The particular journal and author guidelines are indicated. Each article is formatted according to the journal requirements, which causes stylistic disparities concerning font, line spacing, and referencing styles in Chapters 4-6. The main referencing style applicable to the rest of the thesis (Chapters 1-3 and 7) is the Cape Peninsula University of Technology (Harvard) method.

## SCHOLARLY CONTRIBUTIONS FROM THIS WORK

Phase	Presentation	Publication
<b>Phase 1: Visual-based narrative inquiry</b>	1. Jansen, R. & Reid, M. Interest in communication technology by rural caregivers of adolescents with mental health issues: the Mmogo Method®. Oral presentation at the 7 <sup>th</sup> Annual Free State Provincial Health Research Day, Bloemfontein (9 November 2018). 2. Jansen, R. & Reid, M. Exploring rural caregivers' challenges and their interest in communication technology when caring for adolescents with mental health issues: using the Mmogo-method®. Poster presentation at the 16 <sup>th</sup> International Conference on Communication in Healthcare (Porto, 2 September 2018).	Jansen, R., & Reid, M. (n.d.-b). Interest in communication technology by rural caregivers of adolescents with mental health issues in South Africa: The Mmogo-method®. Issues in <i>Mental Health Nursing</i> . <a href="https://doi.org/10.1080/01612840.2020.1774017">https://doi.org/10.1080/01612840.2020.1774017</a>
<b>Phase 2: Systematic review</b>	1. Jansen, R. & Reid, M. Communication technology support for caregivers of adolescents with mental health issues: a systematic review. Poster presentation at the SA ACAPAP National Congress, Johannesburg (25 May 2019).	Jansen, R., & Reid, M. (n.d.-a). Caregivers of adolescents with mental health issues using communication technology: A systematic review. <i>JMIR MHealth and UHealth</i> . <a href="https://doi.org/10.2196/13179">https://doi.org/10.2196/13179</a>
<b>Phase 3: Framework</b>	1. Jansen, R. & Reid, M. Components in developing a communication technology initiative for rural caregivers. Oral presentation at the 17 <sup>th</sup> International Conference on Communication in Healthcare (San Diego, 29 October 2019).	Jansen, R. & Reid, M. A framework for developing an mHealth initiative to support rural caregivers of adolescents with mental health issues. Submitted to <i>Mass Communication and Society</i> .

## CONCEPTUAL AND OPERATIONAL DEFINITIONS

### ***Adolescent***

Adolescence is a period of developmental and human growth during the transition from childhood to adulthood. Transitions might disturb an adolescent's daily functioning and affect their mental health (WHO, 2014; Dogra et al., 2002). The adolescent shifts, from being a dependent to an independent individual (Casey et al., 2010), and experiences cognitive, physical, social, emotional, and behavioural changes during this period (Halter, 2018; APA, 2002). An adolescent is described as a person between the ages of 10 and 19 (WHO, 2014), and includes a number of terms, namely child, youth, young adult, or young person (WHO, 2017). For the purpose of this study, the researcher will consider an adolescent to be between 10 and 19 years, with a mental health issue.

### ***Caregiver***

Caregiver refers to persons, usually parents and/or family members and relatives, friends and/or community members, such as neighbours, living with or near the care recipient (Dixe et al., 2019; Gérain & Zech, 2018; Brown & Brown, 2014; National Alliance for Caregiving & AARP, 2015; Deeken et al., 2003). There is generally a close relationship between the caregiver and the care recipient. Caregiving is informal in nature (Stavrou et al., 2017), in the sense that no professional training is required, no working contract or payment exists between the parties and there are no official working hours (NYC Department of Aging, 2017; Stavrou et al., 2017; Bastawrous, 2013; Reinhard et al., 2012). In this study, a caregiver refers to a parent, family member, neighbour or friend within the community who has accepted the informal responsibility of caring for an adolescent with a mental health issue.

### ***Framework***

Frameworks guide a researcher to plan, organise, identify and define interrelated concepts offering the foundation of a research process (Kivunja, 2018). Such a framework schematically serves as the conceptual underpinning of programme planning (Knowlton & Phillips, 2013; W.K. Kellogg Foundation, 2004). By developing a framework, the researcher can rationalise the theoretical constructs used in the research project (Polit & Beck, 2017). In this study, the researcher developed a mobile health communication framework applicable to caregivers of adolescents with mental

health issues. The framework is structured by the integrated model of behaviour prediction, and the theory-of-change logic model, with content populated by triangulated data obtained from phased data collection. The framework focuses on a rural setting.

### ***Mobile health communication***

Mobile health (mHealth) communication refers to wireless communication technology and a platform to support health services through the use of portable electronic devices, such as cell phones (Källander et al., 2013; Barton, 2012). For the purpose of this study, mHealth communication will refer to using mobile phones to support caregivers of adolescents with mental health issues.

### ***Mental health issues***

Defining mental health issues is challenging due to variable cultural interpretations of behaviour (Videbeck, 2020) and mental dysfunction (Halter, 2018). Mental health issues can be conceptualised as the middle ground between mental well-being and mental health disorders or illness (Halter, 2018). A mental health disorder/illness is associated with clinically significant criteria indicative of a specific diagnosis (American Psychiatric Association, 2013), while a mental health issue may present cognitive, emotional or behavioural problems (Veldman et al., 2015). Throughout this thesis, the term mental health issue will primarily refer to behavioural, emotional or cognitive problems that are observed, without it being formally diagnosed by a healthcare professional.

### ***Rural***

A rural setting pertains to factors that are environmental (sparsely populated, fewer houses and service providers), interpersonal (leisure lifestyle, traditional set of behaviours and beliefs) and intrapersonal (reluctant to make changes and social power structures) (Loue & Morgenstern, 2001). Additionally, a rural setting is characterised by a lack of urban economic core, poor infrastructure and transport challenges (Atkinson, 2014; Visagie & Schneider, 2014; Gaede & Versteeg, 2011). For the purpose of this study, rural area refers to the towns of Springfontein and Trompsburg in the Kopanong local municipality of South Africa.

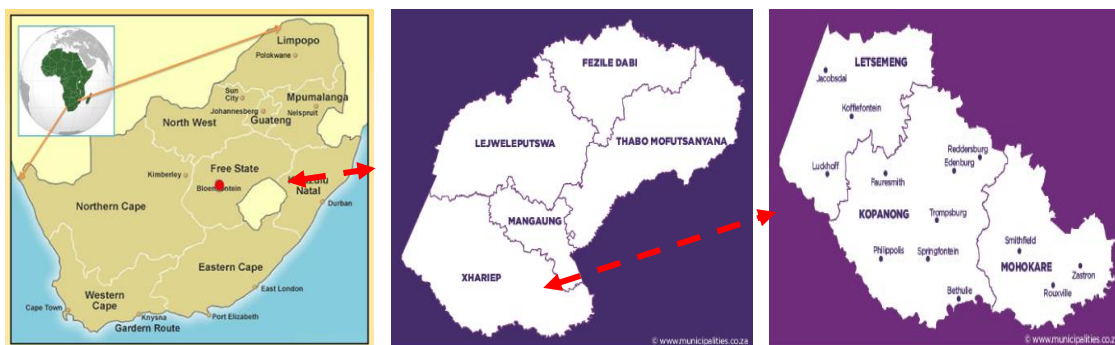
### ***Strengthening positive behaviour***

Behaviour refers to any action, intention, response, psychological reaction or feeling displayed by an individual, which is observable and measurable. Behaviour can occur under specific antecedent situations in conjunction with the environment. Behaviour that is beneficial to an individual, as well as other people, is positive behaviour (Abraham & Denford, 2017). Positive behaviour takes a variety of forms, such as understanding another's needs, desires and goals, and supporting it. A positive consequence of the behaviour will motivate an individual to repeat that behaviour, a frequency in performing more positive actions (Fishbein & Ajzen, 2010; Zastrow & Kirst-Ashman, 2007). For this study, improved caregiving practices and behaviour demonstrated by the caregiver of an adolescent with mental health issues was considered to be positive behaviour. Positive behaviour will be explained through the integrated model of behaviour prediction. Such positive behaviour should be strengthened to ensure that it continues.

## CONTEXT OF THE RESEARCH

Xhariep district is situated in the southwestern part of the Free State province of South Africa, covers an area of approximately 37 673.74 km<sup>2</sup>, and has a population of approximately 146 000, making it the most sparsely populated district in the province. The population consists of Black Africans (72.52%), Coloured<sup>1</sup> people (17.83%), White people (9.62%) and Asian people (0.04%). The main languages spoken in the district are Sesotho (45.32%), Afrikaans (31.56%), isiXhosa (15.81%), Setswana (3.51%) and English (1.60%). Statistics South Africa estimates that 69% of this population is below 35 years of age (Department of Health, Free State, 2018; Xhariep Municipality, 2011).

Kopanong municipality falls under Xhariep district. Xhariep district comprises four local municipalities (Kopanong, Letsemeng, Mohokare and Naledi) and 20 towns. Kopanong municipality includes nine towns, of which two, Trompsburg and Springfontein, were the focus of the study. Trompsburg is classified as a village and Springfontein as a remote village. Each town has a primary healthcare clinic, and Trompsburg has a hospital. Both clinics are accessible to residents within five kilometres of town. Kopanong municipality forms the middle section of the district and covers the largest area of the Xhariep district, with a population of about 49 000 (Njenga, 2015; Xhariep Municipality, 2011). See Figure 1 below.



*Figure 1. Xhariep district with Kopanong municipality in the Free State province, South Africa*

Source: Department of Health, Free State (2018)

<sup>1</sup> In southern Africa, the term Coloured has a specialised meaning in that it denotes a person of mixed racial ancestry.

## CHAPTER 1: OVERVIEW OF THE STUDY

*“You can only learn by opening yourself up to engage with different sources of information. How can you learn something if you never see it, read it or hear it?”*

*-Fran Tarkenton<sup>2</sup>-*

### 1.1 INTRODUCTION

This chapter will provide a comprehensive overview of the thesis. First, the chapter will expand on relevant background to the study, which will be followed by the problem statement and the aim and associated research questions. Next, this chapter will explain the methodology and theoretical foundation of the entire research study. The researcher will, then, briefly introduce the three phases that comprised the study. Thereafter, the chapter will continue with a concise description of the rigor and trustworthiness of the study, and measurement errors. Lastly, the chapter will conclude with a summary and overview of how the thesis is organised.

### 1.2 BACKGROUND

Mental health is a vital and important component of an individual's health. It forms the foundation for healthy development and mental wellbeing. A mentally healthy individual displays self-awareness is self-directive, well adjusted and generally stress free, and demonstrates the ability to cope with normal daily stressors (Videbeck, 2020; Halter, 2018). Such individuals may experience some stress but can adjust to their circumstances due to effective underlying mental functioning (Nizette & Barkway, 2017). Risk factors contributing to the development of poor mental health are psychological, social, cultural, economic, and environmental in origin, e.g., genetics, deprived nurturing, poverty and negative life circumstances (Videbeck, 2020; Burns, 2016; United Nations, 2014). These factors can lead to regular and unsuccessful dealings with stressors, maladjustments, and maladaptive behaviour that impair daily functioning. Significant clinical deviations in functioning in the

---

<sup>2</sup> <https://www.inspiringquotes.us/author/2642-fran-tarkenton>

biological, psychological, cognitive, behaviour and social domains can negatively impact the development of mental health, especially during adolescence (Burns, 2016). Adolescents are becoming increasingly prone to mental health issues due to multiple interacting factors in adverse circumstances in their daily lives (Nizette & Barkway, 2017; Scott et al., 2015).

Childhood adversities and social determinants present a high risk for the development of mental disorders throughout a person's lifespan. These factors contribute to adjustment problems in adolescents worldwide. Child and adolescent mental health contribute considerably to the global burden of diseases. Sadly, the mental health needs of this population in low and middle-income countries (LMIC) are generally ignored, despite the detrimental effects of mental health disorders and their consequences for the individual and the community (Nizette & Barkway, 2017; Burns, 2016; United Nations, 2014; Barry et al., 2013).

It is important to understand how child and adolescent mental health forms part of the backdrop to the high prevalence of mental health disorders globally. Globally, mental disorders show a high prevalence, chronicity and morbidity. The World Health Organization (WHO) reports that untreated mental health disorders account for 13% of the total global burden of diseases (WHO Executive Board, 2011). Results from the Global Burden of Disease study in 2013 illustrate that the burden of mental health disorders increased by 45.0% from 1990 to 2013 (Vos et al., 2015). Mental and substance use disorders are the leading cause of the non-fatal burden of disease and disability worldwide. It is measured in disability-adjusted life years (DALYs) and accounts for 7.4% of the global burden of disease (Whiteford et al., 2013). According to global DALYs, mental and substance abuse disorders are nearly 1.3 times higher in developing countries (Whiteford et al., 2015), where they continuously contribute to the burden of disease.

An increase of 130% in the burden of mental and substance use disorders are expected by 2050 (Whiteford et al., 2016), due to population increase. The world can expect to see gradual growth in population numbers. Over half of the worldwide population increase from 2017 to 2050 is expected to occur in Africa. Furthermore, 41% of the youth population in Africa in 2017 was under 15 years old, while 19%

were aged between 15 and 24 years (Nyamongo & Shilabukha, 2017; United Nations, 2017). An increase in population numbers of LMIC also presages an increase in mental health disorders (V. Patel et al., 2018), with a high onset during adolescence. According to the United Nations, the world youth population (15-24 years old) during 2019 was recorded as numbering 1.2 billion, with sub-Saharan Africa at 211 million (United Nations, 2019). South Africa's population aged between 10 and 19 years numbered approximately 10 000 000 million (Stats SA, 2019) of whom, based on global estimates, 10-20% have mental health issues (De Menil & Glassman, 2015; Scott et al., 2015; Gore et al., 2011). Prevalence studies on adolescent mental health are lacking in South Africa (Mokitimi et al., 2019). Whiteford et al. (2013) report that mental and substance use disorders peak in adolescence, from the age of 10 years, causing disability primarily among this age group (Erskine et al., 2017). In South Africa, mental health disorders are the third-highest contributor to the local burden of disease, and the prevalence of mental health disorders in the child and adolescent group is increasing (Melorose et al., 2015).

This increase in the prevalence of child and adolescent mental health disorders is cause for concern in South Africa. Severe emotional and behavioural difficulties are common among adolescents in South Africa, due to the diversity of the population that presents many challenges related to the variety of cultures, socio-economic statuses, belief systems, life stressors and languages (SA Federation for Mental Health, 2018; Jhazbhay & Karim, 2016). Cortina et al. (2012) found that, in South Africa, one in 10 children/adolescents has a specific mental health disorder, while one in seven children/adolescents has difficulties with mental health.

Mental health issues are strong predictors for developing a mental health disorder. Unless it is detected early enough, a broad range of mental, emotional and behavioural issues may lead to the development of mental health disorders (Swaminathan, 2016). Adolescence is a challenging period due to the presence of abovementioned issues that could compromise people's mental health. Failure to address these emerging issues can have a negative impact on adolescent development, as well as on their social, psychological and economic integration

(Burns, 2016; Paruk & Karim, 2016; Barry et al., 2013). A continuum of mental health issues raise concerns about adolescents' mental well-being and daily functioning.

Recognising these mental health issues during adolescent developmental stages may prevent the development of chronic disorders (Loughlin et al., 2017). Failure to detect mental health issues timeously could have a major impact on public health, with far-reaching consequences (Pinto et al., 2014; Patel et al., 2011), namely, an increase in the burden of non-communicable disorders, a lack of resources, and health inequalities (Dookie & Singh, 2012; Lund et al., 2012). These authors attribute the strain mental health issues cause for public health services to South Africa's historical background, which caused inequalities in healthcare service delivery. Resource-constrained areas have additional pressing healthcare needs, including integration of mental health services, too few skilled healthcare professionals, poor infrastructure and limited resources (De Kock & Pillay, 2016; Thomas & Wightman, 2015).

At the crossing point of mental health care solutions that enhance mental healthcare delivery, lies task shifting or sharing (Weinmann & Klinikum, 2016; WHO, 2008a). South Africa embarked on this pragmatic solution to address healthcare workforce challenges. Task shifting became a natural affair in rural settings when public healthcare demands increased (Maconick et al., 2018; WHO, 2008a). Shifting or sharing of healthcare responsibilities usually become the responsibility of community care workers, unspecialised or lay workers and informal caregivers (Musyimi et al., 2017; Kakuma et al., 2011). Informal caregiving roles are fulfilled by caregivers, such as parents, family members or even neighbours (Dixe et al., 2019; Gérain & Zech, 2018; Verbakel, 2018) taking care of various care recipients. Care recipients could include individuals with chronic conditions, physical or mental health difficulties (Stacey et al., 2012; Taylor-Brown et al., 2014). Caring for adolescents with mental health issues is burdensome (Bademli et al., 2017; Penning & Wu 2016; Oruche et al., 2012). Adolescents face a critical risk for developing mental health issues because of developmental transitions during adolescence, thereby challenging their caregivers.

Caregivers play a vital role during the adolescent's developmental period, especially when they face adverse mental health issues and stressful situations. Some caregiver responsibilities include emotional and social support, psychosocial stimulation, lay counselling and activities relating to daily living and mental health awareness (Bauer & Sousa-Poza, 2015; Smith & Milano, 2014; Ambikile & Outwater, 2012). Research studies have identified particular challenges that caregivers experience when caring for adolescents with a mental health issue. These challenges include low public awareness and, consequently, little social support, as well as unmet caregiver needs related to the identification and handling of mental health issues. These challenges aggravate the caregiver's sense of being stigmatised by the community due to the adolescent's "behaviour", and are exacerbated by caregiver's lack of knowledge (Kelleher, 2019; Steding, 2016). Caregivers are oblivious to "problematic mental health behaviour" because they possess limited information and receive little support in relation to dealing with adolescent developmental transitions and known occurrence of mental health issues (Kelleher, 2019; Leventhal, 2018). Caregivers in South African households may experience particular difficulties due to extended family composition, considering that members from several generations often live in a single home (Martin & Zulaika, 2016). These living arrangements could contribute to caregivers being burdened by a variety of responsibilities, which causes the signs of possible mental health issues in adolescents in their care being overlooked.

Caregivers are uniquely positioned to notice any behavioural or mental health changes in adolescents, but sometimes fail to do so (Sayal et al., 2010). Alternatively, caregivers are not knowledgeable enough about mental health issues to detect signs of mental health issues (Clack, 2016), causing challenges that impact caregiver and adolescent well-being. Consequently, adolescents depend on their caregivers to identify mental health issues and seek help for them. Help-seeking behaviour is restricted by caregivers' perceptions and lack of information about mental health issues (Reardon et al., 2017). Using health services is curtailed by the caregivers' attitudes and beliefs about mental health issues (Steding, 2016). Caregivers also have trouble conversing about emotional or behavioural matters with healthcare professionals, due to embarrassment and stigmatisation of mental health

issues. Similarly, caregivers' cultural beliefs influence their views on the appropriateness of discussing it with healthcare professionals. Rurality also contributes to challenges experienced by caregivers of children with mental health issues, particularly isolation, poverty, lack of knowledge, increased stigmatisation and limited availability of services (Halter, 2018; Patil et al., 2016; West, 2013).

Patel et al. (2016) and Robila (2016) state that caregivers play an important role in preventing mental health issues, especially at community level. Addressing caregiver challenges and their unmet needs could enhance caregiving practices, thereby assisting in preventing mental health issues (Stavrou et al., 2017; Feinberg & Levine, 2015). Several unmet support needs, including informational (Ford et al., 2016), training (Kadungure, 2017), social support (Reardon et al., 2017), emotional support (Talley et al., 2014) and spiritual support (Pelentsov et al., 2015) are documented in the literature. Caregivers' support needs should not be neglected. It is important to support rural caregivers in their caregiving practices of adolescents with mental health issues with applicable initiatives. Supporting these caregivers through information could potentially strengthen their caregiving behaviour and ensure improved caregiver well-being and outcomes for adolescents (Stavrou et al., 2017).

### **1.3 PROBLEM STATEMENT**

Traditional technologies used various media, that is, television, radio, and landline telephone, to disseminate health information to large audiences (Noar & Harrington, 2012; Tanvatanakul et al., 2007). Modern communication technologies, including mobile phones, computers and the Internet, are beneficial for healthcare services, because it can reach people in resource-poor settings, deliver information to large audiences, and enable access to healthcare services (Hollis et al., 2015; David, 2001). Communication or digital technologies terminology is used interchangeably in the literature. Digital healthcare technologies (digital health) emerged from electronic healthcare (eHealth) and were tapered into mobile health (mHealth) technology (Istepanian & Woodward, 2017; Mechael et al., 2010). The promise mHealth communication technology, e.g., mobile phones and other mobile devices, holds for transforming healthcare has captivated researchers for over a decade (Marin et al., 2017; Wilhide III et al., 2016).

Pienaar (2015) reports that using mobile cellular interventions in South Africa has positive effects, and can be an effective health communication strategy for chronic disease management. Mobile phones have the potential to change healthcare across the globe, and particularly in LMICs, where healthcare infrastructure and services are often inadequate (Watkins et al., 2018; Farrington et al., 2014; Kahn et al., 2010). According to the latest available statistics, around 91% of South African households have access to at least one mobile phone (Pew Research Centre, 2018). Opportunities for exploiting mobile communication technology in healthcare have developed over the last few years due to high mobile phone penetration. Mobile communication technology has the potential to improve access to healthcare in primary care settings (Aceto et al., 2018; Perrino et al., 2018; Källander, 2010).

Mobile phones can be used to support and/or deliver mental healthcare among various enterprises and populations, emphasising practical, cheap and easy-to-use resolutions in resource-poor settings. mHealth technologies offer new capabilities for caregivers to get support and information regarding caregiving practices (Aceto et al., 2018; Malvey & Slovensky, 2014). Embracing the use of mHealth communication technology in resource-poor settings has huge potential for providing support to caregivers assisting in caregiving behaviour.

It can be beneficial to caregivers to have continuous access to information regarding adolescents with mental health issues. mHealth initiatives targeted to support caregivers during caregiving practices could influence their caregiving behaviour (Chacko et al., 2016; Buhi et al., 2013). Yesufu-Udechuku et al. (2015) support initiatives that focus on the needs of those who care for people with mental health issues. These authors suggest that carer-focused initiatives can be valuable to healthcare services, because of the central role that caregivers play in rural mental healthcare.

Daily caregiving activities of caregivers should be strengthened by applicable initiatives that assist caregiving behaviour. Caregiver behaviour initiatives are imperative to increase their management, problem-solving and social skills (León-Del-Barco et al., 2019), as is experiencing positive emotions towards caregiving (Brown & Brown, 2014). Rexhaj et al. (2017) and Rimer and Kreuter (2006) mention

that developing such caregiver initiatives should be an end-user, rather than a top-down approach. It is critical to design a framework that will transform existing knowledge, behaviour, skills and practices into a mHealth initiative that supports caregivers of adolescents with mental health issues. A framework detailing all components for the proposed initiative should guide the process of planning an initiative (Yardley et al., 2015; Van Houtven et al., 2011).

Such a framework could transform current mental health practices of primary healthcare (PHC) clinics by using mHealth initiatives in a transparent, universal and standardised way, thereby augmenting the continuum of care between caregivers and PHC. In order to transform healthcare behaviour through mHealth technologies, we must consider which aspects of mHealth “work”, for “which” mental health issues, for “whom” and to achieve “what” outcomes. Developing a framework must include thoughts of how to weave the use and usability of a mHealth initiative into its foundation.

Developing a framework for a mHealth communication initiative will work towards supporting rural caregivers of adolescents with mental health issues in a resource-poor setting. This framework should be an end-user (caregiver) initiative that contributes to supporting their caregiving behaviour.

#### **1.4 RESEARCH QUESTION**

What should an mHealth communication framework that is to be used by rural caregivers of adolescents with mental health issues in the Kopanong local municipality consist of?

#### **1.5 AIM**

The aim of this study was to develop an mHealth communication framework for rural caregivers of adolescents with mental health issues in the Kopanong local municipality.

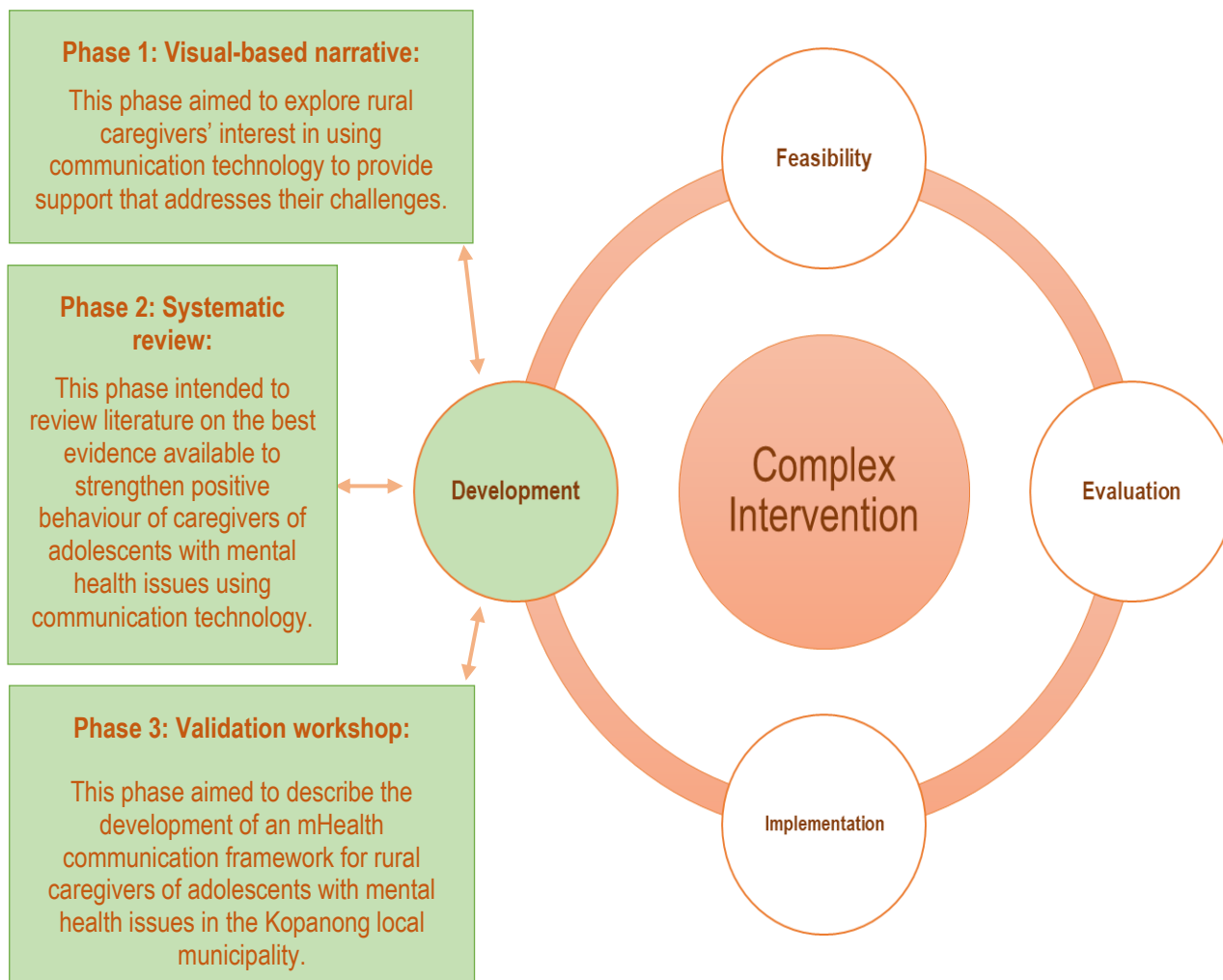
## 1.6 OBJECTIVES

The objectives will contribute to achieving the main aim of the study, and will be pursued in three phases:

- PHASE 1: To explore rural caregivers' interest in using communication technology to provide support addressing their challenges.
- PHASE 2: To systematically review literature on the best evidence available to strengthen positive behaviour of caregivers of adolescents with mental health issues using communication technology.
- PHASE 3: To describe the development of an mHealth communication framework for rural caregivers of adolescents with mental health issues in the Kopanong local municipality.

## 1.7 THEORETICAL UNDERPINNING OF THE STUDY

*This research study was guided by the development of a complex intervention as presented by the Medical Research Council of the United Kingdom that addresses only the developmental stage of the complex intervention (Medical Research Council, 2000). Complex interventions may consist of programmes that are intended to change individuals' behaviour by developing a theory of change framework (Craig et al., 2019; W.K. Kellogg Foundation, 2004). Integral to theories of change within complex interventions, are empirical evidence, contextual influences and desired outcomes (Dhillon & Vaca, 2018; Leeman et al., 2015; W.K. Kellogg Foundation, 2004). Applying a multiple method design in this study contributed to building an evidence base for the complex intervention, including a logical evidence base for the theory of change components. See **Figure 1.1: Positioning of the study's development stage within the complex intervention.***



**Figure 1.1: Positioning of the study's development stage within the complex intervention**

A theory provides the conceptual underpinning of a study by structuring the research process in an organised way according to the vision of the researcher. This blueprint provides the foundation for the construction of each step in the research process and supports decisions that were made to execute it (Grant & Osanloo, 2014; Glanz et al., 2008). Several theoretical frameworks concerning the process of behaviour, behaviour prediction and behaviour change can be used to understand behaviour. More importantly, such theories are critical tools for guiding planning, implementing, and evaluating initiatives.

Theoretical frameworks have the potential to inform decision-making, influence caregivers' behaviour by changing or strengthening it, and provide insight into individual or organisational determinants of intervention adoption (Davis et al., 2015; French et al., 2012; Yzer, 2012). Recognising determinants of particular behaviour may be the first step in designing initiatives that will be successful in diverse populations, especially in healthcare. Behavioural performances of diverse individuals, groups and communities are complex to understand and must be taken in consideration when trying to explain (Fishbein & Ajzen, 2010; Fishbein & Cappella, 2006) a theory of change.

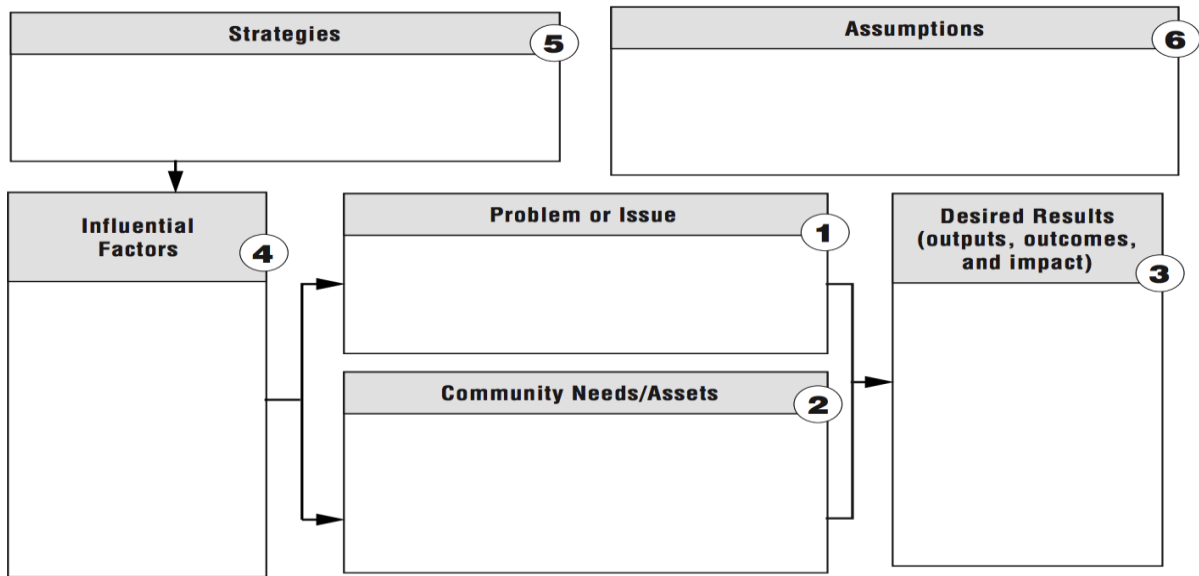
### **1.7.1 Theory-of-change logic model**

Rogers (2014) refers to logic models and theories of change concurrently, while the W.K. Kellogg Foundation (2004) distinguishes between three approaches to logic models, namely, theory, outcomes and activities that influence programme development. A programme in a theory-of-change logic model is defined as the theory of change, intervention, event, policy or strategy, and does not refer to a formal programme. The way that a programme is designed suggests that it will lead to specific outcomes and implies some type of theory of change. A theory of change presents a reasonable explanation of the developmental process related to the intended programme (Rogers, 2014; W.K. Kellogg Foundation, 2004) to improve understanding of a complex process.

The theory-of-change logic model reasons that "if" something is done for the programme population, "then" their behaviour will change (Dhillon & Vaca, 2018;

Funnell & Rogers, 2011; W.K. Kellogg Foundation, 2004). The programme referred to in this study is a programme for caregivers of adolescents with mental health issues. The assumption is that, if rural caregivers are supported, their caregiving behaviour might become more positive towards the adolescent with mental health issues. The framework is expected to trigger the theory of change in caregivers. Thus, the theory-of-change forms the basis in the program development by describing the initiative needed to guide that change in behaviour.

The planning of a theory-of-change logic model framework includes several components explicit to the programme construction. The framework planning focuses on a series of components, namely, 1) the problem statement (the problem the programme wishes to solve), 2) needs of the community (in this study, community refers to caregivers, and needs that relate to the problem), 3) desired results (what the programme expects to achieve), 4) influential factors (barriers/facilitators influencing the community), 5) strategies (identified, evidence-based strategies) and 6) assumptions (belief in the programme's value) (Knowlton & Phillips, 2013; Funnell & Rogers, 2011; W.K. Kellogg Foundation, 2004). (Refer to **Figure 1.2** *Theory-of-change logic model diagram*.) The framework development followed a phased approach (Campbell et al., 2000), which allowed the researcher to propose an mHealth communication initiative for rural caregivers of adolescents with mental health issues. Three consecutive studies were performed to develop the framework and the findings of the multiple research methods were integrated.



**Figure 1.2: Theory-of-change logic model diagram**

Source: W.K. Kellogg Foundation (2004)

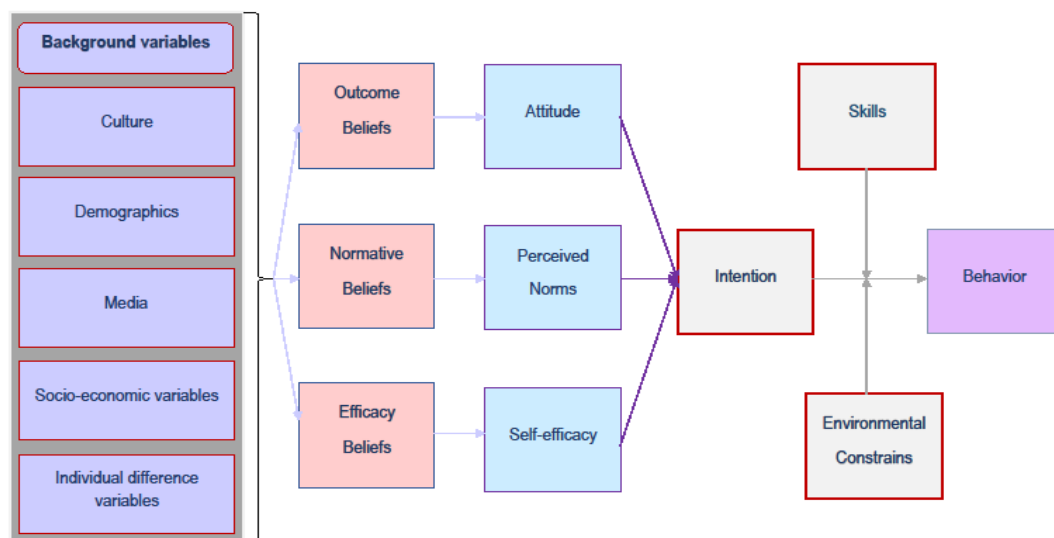
A complex intervention provides a rationale for how behaviour change can be achieved through a programme that is based on several interactive research components (Craig et al., 2019). The programme in the theory-of-change logic model framework of the current study focused on supporting caregivers. A gap potentially exists between caregivers' unmet needs (what is) and the support they need (what should be); this gap could be addressed by the framework. An adequate programme could help caregivers who are intended to receive the mHealth initiative engage in improved caregiving practices, even in complex settings. Programs to support caregiving behaviour should include elements to illustrate behaviour change practices.

### 1.7.2 Integrated model of behaviour prediction

In this study, the researcher decided to use the integrated model of behaviour prediction (IMBP) to describe the determinants of the caregivers' intention to behave, or not to behave positively when caring for adolescents with mental health issues. This thesis leads to the way IMBP determinants can predict positive caregiver behaviour if they are supported by an mHealth initiative. In this respect, this thesis

developed a framework that proposes an mHealth initiative that articulates the behaviour change process in rural caregivers who receive such an intervention.

In this study, the researcher decided to use the integrated model of behaviour prediction (IMBP) to describe the determinants of the caregivers' intention to behave, or not to behave positively when caring for adolescents with mental health issues. The IMBP (presented in **Figure 1.3**) resulted from the integration of several components of various health behavioural theories (including theory of reasoned action and theory of planned behaviour). The concept of self-efficacy as described by Bandura was also incorporated, instead of perceived control. The IMBP is a natural fit in behavioural healthcare (Yzer, 2012; Glanz et al., 2008; Bandura, 1982). Specific determinants provide clues on how intention in relation to behaviour is influenced by key constructs within the IMBP (Admiraal et al., 2013; Fishbein & Cappella, 2006).



**Figure 1.3: Integrated model in behaviour prediction diagram**

Source: Fishbein and Cappella (2006)

According to the IMBP, behaviour is impacted by intention, environmental factors (constraints or facilitators), and skills. Intention is influenced by three primary

determinants, that is, attitude, perceived norms and self-efficacy. Underlying beliefs about the outcome of performing the behaviour, normative beliefs, and efficacy in carrying out behaviour are influenced by the individual's attitude, perceived norms and self-efficacy. Culture, demographics, media, socio-economic variables and individual differences affect the underlying beliefs. All these predictors, in turn, influence the intention to behave in a certain way (Cao et al., 2014). Predictors of intention, attitudes, norms and self-efficacy in relation to performing given behaviour may differ according to population and culture. In addition to these determinants, performance of the behaviour can be positively or negatively be influenced by skills and environmental factors.

An individual may be motivated to act on intentions, but may not have the abilities (skills) and environmental means to do it. Recognising these determinants that influence the intention to perform behaviour is important in the planning of mHealth initiatives (Fishbein & Ajzen, 2010; Glanz et al., 2008; Fishbein & Cappella, 2006). The IMBP can inform the researcher about the intentions of a specific population to perform specific behaviour, or not (Pember, 2017). These predictors determine behaviour, either separately or in a combination (Fishbein & Ajzen, 2010; Glanz et al., 2008; Fishbein & Cappella, 2006). The description of the integrated model above makes it clear that behaviour can be influenced through changes in behavioural skills, environmental factors, and behavioural intention. The researcher critically examined the theoretical stance that associates best with multiple methods research and aligned it with a pragmatic approach.

## **1.8 DESIGN OF THE STUDY**

This section presents a description of the overarching research approach, the paradigm and the research design. This PhD study adopted a multiple method research design. A multiple method research design is susceptible to various methodological formations, unlike a mixed methods design which can only involve qualitative and quantitative methods. Multiple method designs are adept at addressing various questions posed at each stage and related to the research problem (Hunter & Brewer, 2015). Asking appropriate questions to address the research problem may indicate the necessity to use multiple methods of data

collection. A multiple method approach tends to shape the research by triangulating data and findings so that conclusions can be drawn, thereby contributing to new knowledge (Maxwell et al., 2015). The various data collection methodologies enabled the researcher to corroborate the findings in a pragmatic way, and to finalise the framework development.

## **1.9 RESEARCH APPROACH AND PARADIGM**

Pragmatism is the underlying philosophy of the research methodology in this study. The idea of pragmatism is embedded in the practical conduct of the research process, by identifying what works the best in answering the research question (Morgan, 2014; Teddlie & Tashakkori, 2009; Johnson & Onwuegbuzie, 2004). A pragmatist will adopt the most practical approaches to address the research questions (Teddlie & Tashakkori, 2009). Situating the study in a pragmatic paradigm resonated with the researcher's adaptability in the choice of research methods to answer the research questions. Doing so ensured fewer restrictions on how the researcher carried out the research. Pragmatists emphasise understanding shared meanings – either between two individuals or between different research fields (Morgan 2007). Additionally, Morgan (2014) states that a pragmatic approach is particularly appropriate for analysing human behaviour and solving problems practically, rather than philosophically. Human behaviour can be unpredictable and can influence a study's findings, but taking a pragmatic stance prepares a researcher for adapting to unexpected findings. Triangulation of the findings of multiple methods may justify the answer to the research question.

Central to pragmatism is the application of multiple research methods to answer the research questions; the practical value of dealing with the research problem is embraced. Researchers draw upon the strengths of multiple research methods by aligning themselves with different methodological worldviews (Brierley, 2017; Teddlie & Tashakkori, 2009; Morgan, 2007). The researcher's pragmatic stance leads to her intention to implement multiple methods of research, due to her practical nature as an individual who wished to defend her philosophical limitations. Combining multiple methods based on pragmatism may produce findings that are greater than the sum of the parts. Applying pragmatism enables researchers to employ quantitative or

narrative sources of data, thereby facilitating interpretation of multidimensional experiences (Morgan, 2014; Morgan, 2007). In the current study, the researcher combined multiple methods in order to comprehend the knowledge that would be generated from pragmatic actions, to find a viable solution to the research problem. The following sections will present each phase individually, by introducing three distinct research methods that were used by the researcher to address the research aim.

## **1.10 PHASE 1: RURAL CAREGIVERS' INTEREST IN USING COMMUNICATION TECHNOLOGY**

This section serves as a brief introduction to Phase 1 and presents the research method, information on population and sampling, data collection and the analysis process. The researcher employed the Mmogo-method<sup>®</sup> to explore rural caregivers' interest in using communication technology to provide support to address their challenges.

### **1.10.1 Research method**

The Mmogo-method<sup>®</sup> is a visual-based narrative inquiry that was developed by Vera Roos. Visual-based narrative inquiry employs images and words/text in a partnership to make meaning of participants' experiences in a visual way. The Mmogo-method<sup>®</sup> is a culturally sensitive and structured data collection technique (Roos, 2008). This pragmatic engagement gave the researcher an opportunity to obtain insight into caregivers' experiences while caring for adolescents with mental health issues and, furthermore, to explore their interest in using communication technology to support their caregiving practices.

The Mmogo-method<sup>®</sup> is an interactive process, during which individuals in a group consisting of six to ten participants, first, create their own visual presentations with given material and, thereafter, share it in a group discussion. The material provided should be familiar in the study population's community and, in this case, examples may include clay, grass stalks, wood pieces, beads or wire. (See **Photo 1.1** *Example of containers with material.*) This method depicts insight into the participants' social,

cultural and contextual interactions through shared meanings. Their visual constructions made of cultural material may possibly project their thoughts and behaviour related to the prompt (Roos, 2016; Grobler & Roos, 2014; Chigeza et al., 2013). Roos (2008) propose to use an open-ended prompt, phrased as a statement, to ask in the Mmogo-method® underpinning the proposed research question. Data collection through the Mmogo-method concludes when the researcher photographs all the constructions (Roos, 2016; Hanson, 2012; Roos, 2008).



**Photo 1.1: Example of containers with material**

### **1.10.2 Population and sampling**

The study population comprised caregivers of adolescents with mental health issues in the Kopanong municipality. The researcher conveniently focused only on two of the nine towns under the Kopanong municipality, namely Trompsburg and Springfontein. These two towns form part of the collaborative practice learning platform for students of the Faculty of Health Sciences at the University of the Free State. Participants were recruited with the help of community care workers known through this existing network of stakeholders. The community care workers and school employees assisted the researcher to identify caregivers who had been observed to have adolescents experiencing mental health issues. Participants were, then, purposively selected according to predefined inclusion criteria, namely, that they were the primary caregivers of adolescents with mental health issues (refer to the operational definition), and that they agreed to participate in the study. The

sample size for the study was determined by reaching data saturation in applying the Mmogo-method®.

### **1.10.3 Piloting and refining the Mmogo-method®**

Due to the novelty of the Mmogo-method®, the researcher piloted the first Mmogo-method® group discussion during September 2017 with participants residing in Trompsburg. The researcher realised that the prompt needed some refinement, and some logistical adjustments were needed for the planned data collection. Data gathered here were not included in the main findings.

### **1.10.4 Data collection**

For the purpose of this phase, data were gathered via the Mmogo-method®. All participants were informed about the data collection process, including that photographs would be taken and audio recordings made, their rights and the voluntary nature of research studies. Permission to conduct the study was obtained from all stakeholders and participants (Addenda B, C, E). Data collection took place during September 2017 in Springfontein and Trompsburg. All groups were facilitated by the researcher, who is experienced in relation to communication skills, assisted by community healthcare workers, who acted as fieldworkers.

Data were then collected by applying the Mmogo-method® and presenting the open-ended prompt. The prompt was in Afrikaans, and translated as: 'Please make a picture that depicts the relationship between yourself and the adolescent with the mental health issue that you care for'. Any needs voiced by the participants related to advice, information or the desire for knowledge, were explored further to address the aim of this phase. All these discussions were audio-recorded. Participants' involvement in the Mmogo-method® discussions contributed to the verification of meanings voiced by an individual through member-checking. Member checking ensures the accurate reflection of a participant's description of their accounts, as confirmed by other participants (Teddlie & Tashakkori, 2009). Group discussions concluded with photographs being taken, refreshments being served and debriefing by the researcher.

### **1.10.5 Data analysis**

Group discussions that had been recorded were later transcribed verbatim by a professional transcriber and then translated into English. These transcribed texts were analysed thematically and independently by the researcher and a co-data analyst. Analysis of textual data (audio recordings) followed the six steps proposed by Clarke and Braun (2013). The six steps are to familiarise oneself with the data, to code the data, to search for similar themes, to review themes, and to define, name and write the themes up. The researcher and co-data analyst each went through these steps independently. Additionally, the researcher and co-data analyst examined the visual data (photos taken of participants) according to the six-step analysis proposed by Roos and Redelinguys (2016). This six-step approach involves a description of the participants' context, taking an empathic viewpoint, and describing the visual elements depicted on each photo, both literally, as well as the symbolic meaning attributed to it by the participant, defining participant-introduced context and, lastly, conducting an explanatory analysis. Afterwards, both the researcher and co-data analyst triangulated themes developed from the textual and visual data.

## **1.11 PHASE 2: SYSTEMATIC REVIEW**

Next, the researcher conducted a systematic review as Phase 2 of the study in order to search for the best available evidence on using communication technology with caregivers of adolescents with mental health issues. This is the first time, to our knowledge, that a systematic literature review, on this topic has been done. The researcher was guided by the seven-step approach of Higgins and Green (2008), though only the first six steps of the systematic review were implemented, as summarised in **Table 1.1**. Where Higgins and Green propose formulation of concluding statements as a seventh step, the researcher organised data into thematic conclusions after the sixth step.

**Table 1.1: Summary of the systematic review' six steps**

<b>Step 1</b>	Identification and formulation of a focused review question
<b>Step 2</b>	Generation of a search strategy
<b>Step 3</b>	Execution of the search and selection of the relevant studies
<b>Step 4</b>	Performing the critical appraisal and evaluating the methodological quality of selected studies
<b>Step 5</b>	Extracting data
<b>Step 6</b>	Analysing and synthesising the data

### **1.11.1 Review question**

The question that guided the systematic review process was based on the PICO format (PICO = population, intervention, comparison intervention, outcome) (Gough et al., 2012). The aim of the question was to provide a critical review and synthesis of the best available evidence about the topic. The following question was set for this study: “What is the best evidence available to strengthen positive behaviour of caregivers of adolescents with a mental health issues using a mobile health communication intervention?”

### **1.11.2 Search strategy**

A systematic review was done to identify, appraise and discuss available literature on the best evidence available to strengthen positive behaviour of caregivers of adolescents with mental health issues using communication technology. A systematic review involves an examination of research literature; the examination is undertaken systematically and explicitly according to a detailed plan, in order to answer a research question (Munn et al., 2018; Yost, 2014; Gough et al., 2012). This systematic review was registered in PROSPERO (CRD42018094680), and the review was carried out in line with PRISMA guidelines.

A systematic search was conducted of the literature from 1 January 2007 to 2 August 2018 on electronic databases that included the platforms EBSCO Host and Scopus database. No language or study design restrictions were applied. A senior

librarian used a search string with Boolean operators to retrieve articles suggested by the researcher and promotor.

### **1.11.3 Eligibility criteria and selection procedure**

For the purpose of this review, the researcher was interested in articles focusing on pre-identified eligibility criteria with the following characteristics, based on the PICO:

- **Population:** Caregivers, namely families, parents, siblings and relatives of adolescents with mental health issues (concentrating on depression, anxiety and substance use disorders).
- **Intervention:** Articles that reported on communication technology interventions.
- **Comparison:** Routine communication technology.
- **Outcome:** A description of IMBP outcomes depicted among the caregivers after using communication technology.

Articles were excluded if the focus was only on adolescents, reported on mental-health-related therapies or traditional communication interventions. All articles retrieved from the search were filtered against the review question and eligibility criteria, focusing on the title and abstracts. Full-text articles of potentially relevant studies were then retrieved and reviewed independently by the researcher and the promotor.

### **1.11.4 Quality appraisal**

The study appraisal involved evaluating quality by using the critical appraisal skills programme (CASP) (2014) and Joanna Briggs Institute (2014) assessment tools applicable to each study design. Two senior researcher assisted with the critical appraisal process (see Addendum F). Furthermore, the researcher determined the hierarchy of methodology and the classification system in terms of research design according to the American Dietetic Association scoring system (2012).

### **1.11.5 Data extraction, analysis and synthesis**

After the critical appraisal, all data were extracted into a table in a Word document. This document contains columns to describe the studies and classify the extracted data related to methodology, outcomes and intervention, critical appraisal and study findings related to the IMBP (see Addendum G). A meta-analysis was not feasible, due to the heterogeneous nature of studies that were included. The researcher carried out thematic data analysis and synthesis. The promotor checked extracted data and coding.

### **1.11.6 Development of draft framework**

The researcher developed a draft framework informed by the theory-of-change logic model for an mHealth communication initiative to support rural caregivers. Drafting this framework was based on triangulation of research findings from Phases 1 and 2 as well as additional literature. The researcher developed the draft framework by outlining components relating to assumptions, the problem statement, community needs, desired results, influential factors and evidence-based strategies.

## **1.12 PHASE 3: VALIDATION WORKSHOP**

Phase 3 aimed to validate the draft framework for an mHealth initiative for rural caregivers of adolescents with mental health issues, developed based on the data from phases 1 and 2, by visualising the components while being guided by the theory-of-change logic model. The process of generating a framework based on the theory-of-change logic model is more effective when a comprehensive range of participants is involved during the development (Shakman & Rodriguez, 2015; Knowlton & Phillips, 2013; W.K. Kellogg Foundation, 2004).

### **1.12.1 Population**

The researcher purposively invited expert stakeholders working in, or involved in various mental health fields, as well as key role players in policymaking related to adolescents, to participate. These stakeholders consisted of interprofessional

experts from the Department of Health, the Free State Psychiatric Complex, a church organisation and academia.

### **1.12.2 Validation workshop**

This one-day workshop was held on 20 November 2019 in the NARS Building at the School of Nursing of the University of the Free State. This venue was accessible to all the stakeholders and conducive to present such a workshop. The facilitator informed the stakeholders of their rights, supplied information leaflets (Addendum H) and asked their permission to audio record the session. She also explained the workshop process and sought written consent (also Addendum H). The researcher then presented the study's background, aim and findings from Phases 1 and 2. Then, the promotor facilitated the workshop by introducing each component of the draft framework to the stakeholders. She facilitated the workshop through a "forward and backward mapping" process.

### **1.12.3 Finalising the framework**

The facilitator used a mapping process throughout the validation workshop, thereby verifying all the framework components. This forward and backward mapping ensured clarity for all parties involved. The expert stakeholders reached consensus about the draft framework, which made it possible to finalise the framework.

## **1.13 METHODOLOGICAL INTEGRITY**

Methodological integrity in multiple method research studies determines the trustworthiness, quality and legitimacy of activities undertaken during the research process (Frels et al., 2015; Onwuegbuzie et al., 2011). The researcher ensured methodological integrity during each phase. **Table 1.2** *indicates the methodological integrity applied in each phase.*

**Table 1.2: Methodological integrity applied per phase**

Phase	Elements of quality	Application
Phase 1: Visual-based narrative inquiry	Credibility: truth in the findings	Triangulation of textual and visual data. Member checking during group discussion.
	Dependability: consistency in results	Triangulation of textual and visual data. Audio recordings, audit trials, detailed documentation.
	Transferability: applicability to other settings	Rigorous methodology, description of study context.
	Confirmability: accuracy of the findings	Data collection by researcher assisted by community healthcare worker (fieldworker).
	Authenticity: presentation of reality	Contextual description and photographs
	Verisimilitude: believability and truthfulness	Recordings and photographs of group discussions.
Phase 2: Systematic review	Rigour	Used multiple sources of data (electronic data, checked reference list, grey literature and contacted author).
	Methodological quality and bias	Used applicable appraisal tools relevant to study design, multiple senior researchers assisted in quality appraisal.
	Transparency	Record-keeping was meticulous.
Phase 3: Workshop	Inference quality	Audit trial of conclusions made based on findings of Phases 1 and 2.
	Design quality	Workshop as most appropriate research method implemented to address Phase 3 question.
	Interpretive rigour	Interpretation and integration of findings from Phases 1 and 2 depicted in draft framework confirmed by stakeholders.
	Validity	Expert stakeholders participated in finalising the framework

## **1.14 ETHICAL CONSIDERATIONS**

The Singapore Statement (World Conferences on Research Integrity, 2010) guided the conduct of the researcher in this research study. This conduct should be characterised by professional responsibility, which is fundamental to the integrity of the research. Four ethical principles of the Singapore Statement that are fundamental in guiding the research process are honesty in all aspects of research, accountability in the conduct of research, professional courtesy and fairness in working with others, and good stewardship of research on behalf of others (Lucas, 2010; World Conferences on Research Integrity, 2010). Ethical clearance was obtained from the Health Sciences Research Ethics Committee of the University of the Free State (HSREC 47/2017 (0349) (Addendum B), as well as institutional approval from the Free State Department of Health (Addendum C). Permission was also granted by the Health Sciences Research Ethics Committee to change the study's title (Addendum D). The researcher implemented the following ethical considerations.

### **1.14.1 Honesty in all aspects of research**

The researcher explained and disclosed the research process thoroughly to all the participants during Phase 1 and Phase 3. A detailed and honest description of the methodological approaches was provided through information leaflets (see Addenda B, C, E, H). The systematic review presented an accurate representation of data extraction and interpretation. All the contributions that were made are acknowledged in the articles. The researcher is forthright about limitations in the data collection findings during the first two phases and did not omit any information or deceive any member participating in the workshop.

### **1.14.2 Accountability in the conduct of research**

The researcher was sensitive about participants' emotional state during the Mmogo-method<sup>®</sup> conducted in Phase 1. She did not exploit any participant or expose participants to any risks during the data collection. During the systematic review, the researcher avoided plagiarism and conducted a transparent review. The researcher

maintained ethical standards during the workshop and managed data with confidentiality. The researcher recorded all documentation pedantically during all the phases.

#### **1.14.3 Professional courtesy to and fairness in working with others**

The researcher acted professionally throughout the research process, especially when in contact with participants, by adhering to all ethical guidelines. A fair representation of the research study and participants' experiences was maintained. The researcher cooperated well with the expert stakeholders, in a professional manner, and accepted their contributions during the workshop.

#### **1.14.4 Good stewardship of research on behalf of others**

The researcher reflected the "voice" of the participants and did not reflect her own perspectives during Phase 1. She avoided selection and language bias by conducting Phase 1 in the language of the participants' choice. Involvement of all the participants were acknowledged in the dissemination and publication of research without making their identities decipherable from the published data.

### **1.15 MEASUREMENT ERRORS**

Errors may occur in research measurement. Adhering to the principles of quality research, these errors should be clearly defined, described and documented during all the steps of the study (Brink et al., 2012). See **Table 1.3** *for examples of possible measurement errors, as well as what the researcher did to limit the impact of such errors on the project.*

**Table 1.3: Possible measurement errors**

<b>Phase 1: Visual-based narrative inquiry</b>	<b>Errors were limited through:</b>
The participants might be concerned that participating in the study will be time-consuming and this could influence their willingness to participate.	Informed the participants that they will only participate in one group session.
Language bias	Assisted by community healthcare workers
Participants may be concerned that their personal information would not be kept confidential.	Made it clear confidentiality was an important factor of the study and that there were measures in place to ensure that the data are kept confidential
Methodological bias	Multiple data sources used (textual and visual data) Data triangulated
Truth value	There was member checking during group discussions
Over involvement of researcher	All observations were recorded by the researcher and fieldworkers throughout the study
Biased sampling	Voluntary and available caregivers participated
<b>Phase 2: Systematic review</b>	<b>Errors were limited through:</b>
Insufficient search strategy	A focused review question was stated. A comprehensive search strategy (multiple sources) was done. Used appropriate databases. An experienced librarian assisted. Studies met the inclusion criteria.
Selection bias	Electronic databases, reference list checking and contact with authors were representative of research. All identified studies were appraised.
Publication bias	Grey literature (dissertations and book chapters) were included.
Language bias	English-language literature, as well as studies in languages other than English, but with an English abstract, were included in the study.

Poor quality publications	Utilised critical appraisal tools. Used two senior researchers.
Poor selection of studies	Defined clear inclusion and exclusion criteria. Thorough documentation were done
<b>Phase 3: Validating workshop</b>	<b>Plan to limit the errors through:</b>
Credibility	Involved expert stakeholder and inter-professional team members.
Methodological rigour	The IMBP and logic model assisted in development, with logic model providing structure of framework.
Validity	Validated by expert stakeholders.
Triangulation	Data triangulated from multiple sources during the study.

## 1.16 STRUCTURE OF THIS THESIS

This thesis is organised into seven chapters, each with its specific focus. **Chapter 1**, the introductory overview, is followed by **Chapters 2 and 3**, which expand on the background literature relevant to this study. These chapters review the existing literature and offer insight into what has already been researched and, thus, what is currently known about the research topic. **Chapter 2** focusses on literature related to the caregiver and the adolescent with mental health issues. In **Chapter 3**, the researcher discusses literature on mobile health communication technology and the caregivers of adolescents with mental health issues. **Chapter 4** reports on the first phase of this research. In this phase, the Mmogo-method<sup>®</sup> was used to explore caregivers' interest in using communication technology to support them while caring for adolescents with mental health issues. This article was accepted for publication in the journal, *Issues of Mental Health Nursing*, May 2020. **Chapter 5** introduces the second phase. This chapter focusses on a systematic review of the literature to investigate the best evidence that is available to strengthen positive behaviour of caregivers of adolescents with mental health issues, by using communication technology. This article was accepted for publication in the journal, *JMIR mHealth and uHealth*, May 2020. **Chapter 6** addresses the third phase of the study. This

chapter describes the validation workshop and introduces the final framework informed by the theory-of-change logic model, while the IMBP is used to explain how behaviour change can occur. This article is under review by the Mass Communication and Society journal. **Chapter 7** concludes with a summary of the research, factual conclusions, conceptual conclusions, implications, recommendations, limitations and concluding remarks.

## **CHAPTER 2: LITERATURE REVIEW: CAREGIVERS OF ADOLESCENTS WITH MENTAL HEALTH ISSUES**

*“Investigate what is, and not what pleases”*

*-Johann Wolfgang von Goethe<sup>3</sup>-*

### **2.1 INTRODUCTION**

This chapter provides context to the study, and strengthens the rationale of the research by examining local and international literature related to the topic of caregivers and adolescents with mental health issues. The researcher followed a rigorous process to review diverse literature obtained via various electronic platforms and databases. This chapter begins with an overview of the caregiver concept, provides general characteristics of caregivers and the profile of South African caregivers, and discusses caregiver prevalence. Next, the researcher offers insight into adolescents with mental health issues, as the care recipients, by explaining mental health issues and related concepts. It was also important to investigate the link between mental health issues and culture and the indicators of mental health issues. This is followed by an exploration of risk factors for adolescents in relation to developing mental health issues and related prevention strategies. Lastly, the impact on caregivers of caring for adolescents with mental health issues is discussed, with a focus on burdens, caregiver well-being, and their unmet needs. A discussion of targeted initiatives for caregivers concludes this literature chapter.

### **2.2 THE CAREGIVER CONTEXT**

Caregiving, as a phenomenon, materialised in the late 18<sup>th</sup> century (Hoffmann & Mitchell, 1998), and was considered to involve activities related to love and duty (Feinberg & Levine, 2015). However, viewing caregiving through this rosy lens conceals the sad truth of caregivers’ daily challenges (Feinberg, 2014). Caregivers are mostly invisible, ignored, and not recognised by community members and

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<sup>3</sup> <https://libquotes.com/goethe/quote/lbg3c7g>

healthcare professionals (Harris, 2018; Feinberg, 2014; Joslin, 2002). There is an increasing research focus on the context in which caregivers provide care.

A high number of caregiver narratives and common themes emerged from this extensive body of work. These caregiver narratives translate into a contextual understanding of caregiver dynamics and caregiving practices in various circumstances. Caregiving is an idiosyncratic process, and each narrative helps to better understand caregivers' experiences (Black, 2014; Talley et al., 2014; Montgomery & Kosloski, 2009; Sawatzky & Fowler-Kerry, 2003). From this exploration of caregiver research, the researcher will highlight the nature of caregiving and the complexity of caregiver experiences.

Caregiving could be rewarding and fulfilling (Gelkopf & Roe, 2014; Greeff & Nolting, 2013); however, most of the time, caregivers face many challenges related to their circumstances (Isa et al., 2016; Jiloha & Kukreti, 2016; National Alliance for Caregiving & AARP, 2015). People in a caregiving role carry significant physical, emotional, or financial burdens (NYC Department of Aging, 2017; Sheets et al., 2014; Talley et al., 2014). All caregivers face caregiving challenges, which inform a collective understanding of the reality of caregiving. Furthermore, the caregiver burden could influence the well-being of care recipients, who are typically individuals with acute or chronic illnesses, the frail or elderly, newborn babies, children and adolescents, and persons with physical or mental health issues (Bingham, 2017; Stacey et al., 2016; Talley et al., 2014; Logsdon & Robinson, 2000).

Caring for a person suffering from mental health issues can even be more demanding on the caregiver (Alzahrani et al., 2017; Bademli et al., 2017; Bhandari et al., 2017; Chang et al., 2016; Chadda, 2014) than caring for persons who do not have mental health issues. Research suggests that caring for children and adolescents with mental health issues can be very intensive and overwhelming (UCLA Center for Mental Health in Schools and Student Learning Support, 2018; National Alliance for Caregiving & AARP, 2015; Talley et al., 2014; Oruche et al., 2012). Caregiving may be further complicated by caregivers who are not knowledgeable about mental health issues, which cause difficulties in managing affected adolescents. If caregivers fail to recognise mental health issues, it may be

due to being uneducated or unskilled regarding adolescents' development and health. Although empirical research narrates that caregivers do not recognise child and adolescent mental health issues, this phenomenon has been neglected in studies (Steding, 2016; Ambikile & Outwater, 2012; Pavuluri et al., 1996). Caregiver recognition of mental health issues may predict their willingness to seek timely help for early detection of a possible mental health disorder, and the management thereof (Reardon et al., 2017; Steding, 2016; Thurston et al., 2016).

Unfortunately, low socio-economic status environments, specific cultural characteristics, and lack of support and resources present more challenges for both the caregiver and the adolescent with mental health issues (Kelleher, 2019; Leventhal, 2018; Ae-Ngibise et al., 2015). Caregivers, as the gatekeepers of adolescent mental health, play a crucial role in rural communities where there is a lack of human and mental health resources (Denby & Bowmer, 2013; Gamm et al., 2003). Parents and close family relatives are usually seen as "caring adults" or "guardians" living with the adolescent. Consequently, all parents are, per definition, seen as informal caregivers, due to their care responsibilities towards children or dependents (Gérain & Zech, 2018). Parental awareness in detecting mental health issues is a vital determinant of adolescent mental health in public health initiatives (Vining, 2019; Abera et al., 2015). The researcher extends concerns about efforts to investigate rural caregivers' role in caring for adolescents with mental health issues and identifying initiatives to support this critical role.

Abera et al. (2015) declare that LMICs need to design public health initiatives for caregivers of adolescents with mental health issues. A review by Thrush and Hyder (2014) states that caregivers in LMICs suffer caregiving consequences, and related research is limited. It will be foolhardy to ignore the burdens that affect caregivers who care for loved ones (NYC Department of Aging, 2017; Brown & Brown, 2014), and researchers should strive to identify active support initiatives (León-Del-Barco et al., 2019; National Alliance for Caregiving & AARP, 2015). Intensifying the development of appropriate initiatives to support caregivers may mitigate a variety of challenges (León-Del-Barco et al., 2019; Magai et al., 2018; Epstein et al., 2015). Regrettably, caregivers feel unsupported (Choate, 2015) and are seldom interested

in information (Ford et al., 2016). The researcher will discuss the concept of caregivers next.

## **2.3 THE CONCEPT OF CAREGIVER**

Some literature differentiates between formal and informal caregivers. Formal caregivers are paid to deliver professional care at home or in facilities, while informal caregivers deliver unpaid care, usually at home (Family Caregiver Alliance, 2016; Stacey et al., 2016; Joubert, 2005). Unpaid caregivers exist in all cultures, worldwide, and some are expected to provide care as a moral duty (Stavrou et al., 2017), or on the grounds of their religious beliefs (Verbakel, 2018). Most caregivers voluntarily dedicate and commit themselves to care for others over the long term without compensation (Greenwood et al., 2019; Van Pletzen & MacGregor, 2013). Informal caregivers, including parents (mostly mothers), family members, friends, other relatives, or neighbours, are responsible for managing the daily activities or providing any additional assistance needed by the care recipient (Verbakel, 2018; Roth et al., 2015; Joubert, 2005).

Sometimes, researchers describe caregivers as non-professional (Dyer et al., 2012) or non-specialist caregivers (Healy et al., 2018). Defining a caregiver can, thus, be problematic, because of diverse caregiver characteristics. Caregivers can be of any gender, age, or race, could care for various types of care recipients, and have different responsibilities (Stacey et al., 2016; Talley et al., 2014). This wide array of caregiver characteristics should be kept in mind to avoid stereotyping this population.

### **2.3.1 Characterising caregivers in general**

Understanding the underlying impact of caregiver characteristics, including gender, age, culture, education background, and relationship with care recipients, could be insightful for a study of caregivers (Hitchner, 2018; Scharlach et al., 2001). Caregiver characteristics can give a comprehensive account of what the caregiver context entails and add insight to the typology. The researcher underscores all meanings of caregiver characteristics and wishes to clarify the concept of caregivers in the current research to obtain a better understanding of the concept.

Women are more likely to assume the role of caregiver than men. A survey of all types of unpaid caregivers in New York City found that the typical caregiver was female, aged on average 50 years (NYC Department of Aging, 2017), with some education, and unemployed (Thrush & Hyder, 2014; Talley et al., 2014). Society usually expects a mother, grandmother, or other female relative to take up the central caregiver role (Penning & Wu, 2016; Thrush & Hyder, 2014; Logsdon & Robinson, 2000). Caregivers are not only parents, grandparents, aunts, or family relatives; and all caregivers should be acknowledged for their know-how, and for serving as the primary caregiver of adolescents with mental health issues (Schor, 2003). Most of these individuals are usually the primary caregivers of children and adolescents (Bademli et al., 2017; NYC Department of Aging, 2017; McIntyre, 2016; Penning & Wu, 2016; Talley et al., 2014). As nurturers, they traditionally provide informal care in the home setting every day (Moore, 2013; Joubert, 2005; Kenkel, 2003).

Furthermore, caregivers supply more than the routine care required of a caregiver – they also have to deliver therapeutic care to children under the age of 18 who possibly have mental health (including behavioural or emotional) issues (Curtin et al., 2017; Barrett et al., 2010; National Alliance for Caregiving & AARP, 2009); in addition, they are sometimes also responsible for managing the whole household. This pragmatic description embraces the significant role that caregivers of adolescents with mental health issues play. They need to care for each person in the house, and cope with different tasks while maintaining the adolescents' mental health during the latter's transition from childhood to puberty, while also caring for themselves (Talley et al., 2014; Oruche et al., 2012; Dogra et al., 2002). The concept of caregiver is not separate from the role of parent or relative but is sometimes culturally restricted to mothers, or women in general.

However, being a woman and a caregiver contributes to role conflict and role overload (Bastawrous & Armstrong, 2013). Older caregivers have to juggle caring for young adults, children, and even grandparents who live in the same household (Larkin et al., 2019). They contribute significantly to the formal healthcare sector in communities, at the cost of an increased caregiver burden (Greenwood et al., 2019; Carmichael & Ercolani, 2014). Older caregivers are becoming more common due to

an aging population (Larkin et al., 2019; Triantafillou et al., 2010). South African caregivers share specific characteristics.

### **2.3.2 Profile of South African caregivers**

Like women of most nations, South African women are traditionally the primary caregivers of children. They are responsible for childcare and housekeeping too, thus, in specific communities, the family home serves as the caring environment, and family members serve as potential caregivers. South African family composition varies, due to extended family care situations, including multi-generational households, as found in most Black communities (Martin & Zulaika, 2016; Sooryamoorthy & Makhoba, 2016). As a result of these traditional arrangements, children and adolescents experience a series of different adult caregivers over their lifetimes (Hall & Sambu, 2014).

In South Africa, many children do not live with their birth parents or live with only one of their birth parents, usually the mother (Mkhwanazi et al., 2018; Bunning et al., 2017; Rabe, 2017). Woman-headed households are common in South Africa; in these households, mothers, grandmothers or aunts provide care – few men fill the role of caregiver. These living arrangements reflect the stark reality of the absence of father figures in the lives of children and adolescents (Hall & Sambu, 2014). Adolescents who were not raised by their fathers, or at least by another male figure, could indicate that challenges may arise from caregiver-adolescent relationships.

A large percentage of South African children under the age of 18 years live with their grandparents (Martin & Zulaika, 2016), or with relatives in rural settings, sometimes separate from their siblings, while biological parents work in other towns. Caregivers in these circumstances include grandparents, aunts, or even uncles (Hall & Posel, 2019; Hall & Sambu, 2014). Grandparents who assume parental roles face numerous challenges because older persons are generally seen as care recipients, not caregivers (Joubert, 2005). In some cultures, parents or grandparents may feel obliged (Sooryamoorthy & Makhoba, 2016) to care for someone, and they do not see themselves as caregivers (NYC Department of Aging, 2017; Martin & Zulaika, 2016). Verbakel (2018) linked this phenomenon to culture. In some contexts, informal

caregiving is part of usual family life, and caring does not make someone a caregiver. Historically, this care-relationship refers to informal care or kinship care, which involves a close relative being responsible for childcare. *“Nonetheless, kinship care is the least protected and least supported form of alternative care for children”* (Assim, 2013). The various situations described above indicate the fragmentation of caregiver practices, which makes it difficult to determine the prevalence of caregivers. Questions remain about what caregiver prevalence actually is.

### **2.3.3 The prevalence of caregivers concerning children and adolescents**

In the United States in 2014, approximately 43.5 million adults served as unpaid caregivers of adults or children (NYC Department of Aging, 2017). These caregivers were mainly female (66%), and were aged, on average, 48 years. About one third cared for more than two people (34%); a seventh of the caregivers looked after their own children (14%). Furthermore, one-third of caregivers (37%) had children or grandchildren under the age of 18. African-Americans (65%) and Hispanics (63%) were more likely to be primary caregivers than Caucasians (53%) or Asian-Americans (48%) (National Alliance for Caregiving & AARP, 2009). In the European population, the estimated number of informal caregivers ranges from 10% to 25% (Zigante, 2018).

Explaining South African caregiving statistics is more difficult, primarily due to diverse living arrangements and traditions, and extended family settings. The term extended family is a well-known concept in Black populations. An extended family consists of parents (one parent or both), grandparents, aunts, uncles, and even cousins, living in the same household or in close proximity. In South Africa, 62% of children live in such multigenerational households. Extended families occur predominantly in rural communities (Hall & Mokomane, 2018; Mkhwanazi et al., 2018; Amos, 2013) and, thus, it is difficult to find accurate data on the prevalence of caregivers in South African households, where caregiver prevalence statistics are not collated.

In poor households in South Africa, almost 92% of primary caregivers of children are mothers, grandmothers, and aunts (Rabe, 2017; Joubert, 2005). Furthermore, the

2016 Community Survey (Stats SA, 2016) reports that 41% of homes were woman-headed, while 65% of children live in households where grandparent(s), or even great-grandparent(s) were in charge. Some 2.7 million South African children have been reported to live with their grandparents only (Mkhwanazi et al., 2018; Amos, 2013; Amoateng et al., 2007); 39% of these grandparents were younger than 60 years (Hall & Mokomane, 2018). Generally, all household residents share childcare responsibilities.

The researcher understands the context of sharing responsibilities by household members, though it is not clear whether these living arrangements lead to conflict or confusion among the residents regarding caregiving practices. This statement emphasises the importance of understanding the vital roles and responsibilities of caregivers who care for adolescents. Greater understanding of the care recipient in this dyadic care relationship would help to make meaning of caregiver burdens.

## **2.4 CARE RECIPIENTS: ADOLESCENTS WITH MENTAL HEALTH ISSUES**

Conceptual meanings related to the care recipient, namely, the adolescent with mental health issues, will be explored further. The concept of adolescence is not interpreted uniformly – there are numerous definitions, which emphasise a variety of characteristics, from age differentiations to developmental changes, and even the period of transition. Terminology, such as child, youth, young adult, or young person, is all related to the term adolescent, according to the WHO (2017). The WHO defines adolescence as the period between the ages of 10 and 19 years (WHO, 2012a), and refers to the period of adolescence as a time of human growth and development, during which critical changes take place (WHO, 2016a).

Adolescence is characterised by developmental changes that occur between childhood to adulthood (Coovadia et al., 2016; Casey et al., 2010; Dogra et al., 2002). Much has been written, in both the media and literature, about adolescent transitions. Entering adolescence implies cognitive, physical, social, emotional, and behavioural changes (Coovadia et al., 2016; APA, 2002). Adolescence also marks the shift from being dependent, to becoming independent (Casey et al., 2010). It is a unique period of human development. However, rapid transitions might disturb

adolescents' daily functioning and have implications for their mental health (Toska et al., 2019; Dogra et al., 2002). Poor management of changes during adolescence may hinder healthy development and mental well-being and has the potential to cause mental health issues (Child Mind Institute, 2016). Mental health issues frequently appear during adolescence (Patel et al., 2018; Patton et al., 2016).

#### **2.4.1 Mental health issues in adolescence and related concepts**

*Mental health* exists along a severity continuum, which includes mental well-being, behavioural and mental health issues, and mental health disorders. This continuum may range from mental well-being on the one end, to a *mental health disorder* on the other end; in between are normal/abnormal behaviour and mental health issues (McAdam et al., 2018; Dogra et al., 2002). The nature of the middle spectrum of the continuum is challenging to define and covers a broad range of definitions. Interchangeable explanations of behavioural and mental health issues during adolescence appear in literature and contribute to confusion about this concept (Borba et al., 2018). A synonym for mental health disorder, or simply, mental disorder that is used in research is *mental illness* (Radden, 2019; McAdam et al., 2018; Robila, 2016). However, Skylstad et al. (2019), takes another approach to this term: "*Mental illness is used as a term intended to be broader than 'disorder,' and it adheres more closely to the popular understanding of mental processes and illness*".

Another version of mental health terminology is, for example, to use the term *psychiatric disorder*. Stein et al. (2010) refer to mental/psychiatric disorder in their paper and claim it is difficult to operationalise a clear definition. These authors also propose a definition based on the Diagnostic and Statistical Manual of Mental Disorders (DSM 5 manual). According to the DSM 5 (American Psychiatric Association, 2013), mental disorders display as disturbances in cognitive abilities, emotion regulation, or behaviour that reflects dysfunctional biopsychological processes. Radden (2019) states that behavioural conditions are included in the term mental disorder.

*Cognitive, behavioural and emotional problems* are indicative of mental health issues, according to Swaminathan (2016) and Veldman et al. (2015). Dogra et al.

(2002), Swaminathan (2016), Adhikari et al. (2015) and Hoskins (2014) list (externalising) behavioural problems in adolescents as lying, stealing, aggression, school refusal, inattentiveness, insubordination, truancy and substance use. Correspondingly, they all explain (internalising) emotional problems as depressed mood, anxiety, worry, fear, thought disturbances, lack of self-esteem, unhappiness, and anger. A similar understanding of these concepts is that increased levels of *externalising problems* (aggression and hyperactivity), *internalising problems* (anxiety and depressed mood), and dysregulation (sleeping and eating problems) are associated with mental health issues (Ogundele, 2018; Godoy et al., 2014). Internalising and externalising behaviour indicates problem behaviour that leads to mental health issues (Robila, 2016; Hoskins, 2014), which, if not managed timeously, could lead to a chronic mental health diagnosis. Thus, mental health issues refer to all problematic behaviour observed, but not formally diagnosed by a professional.

Another perspective in literature alludes to the term *risky behaviour*, which can cause problems for adolescents, and lead to mental health issues. Some examples of common risky behaviours are substance abuse (alcohol and drugs), gang activities, bullying, and teenage pregnancy (Mfidi, 2017; Pandžić et al., 2017). Mfidi alleged that mental health issues such as mood disturbances originate from risky behaviours. Theft and gang-related activities are classified as *disruptive behaviour*. All these concepts that relate to behavioural problems are used synonymously with mental health issues (Mfidi, 2017). Petrovic and Scholl (2018) claim that a single definition of disruptive behaviour is needed, due to a multitude of classifications, including voluminous lists of synonyms in literature.

Mental health issues and related concepts are interpreted in different ways by various researchers – they are complex and, thus, complicated to describe. Furthermore, it is essential to ask whether uneducated and unskilled caregivers will comprehend the concept of mental health issues when there is minimal consensus in the literature. Caregivers are the people who must decide whether adolescents need help (Valverde et al., 2012), and they base their decision on their concern about the adolescents' mental health and behaviour (Veldman et al., 2015). Similarly, the WHO (2017) reports that many caregivers feel inadequate in the caregiving role, and it is

likely caregivers find it difficult to decide whether an adolescent presents normal adolescent behaviour, or whether their behaviour is indicative of a mental health issue (Campelo et al., 2014).

#### **2.4.2 Mental health issues and the caregivers of adolescents**

Fisher et al. (2011) believe that caregivers are well-positioned to notice changes in adolescents' behaviour because of close living arrangements and family relations. Leon-del-Barco et al. (2019) point out that the family unit can be either a risk factor or, in some cases, serve as protection in monitoring mental health issues in adolescents. In turn, Clack (2016) argues that caregivers' perceptions of whether mental health issues are problematic are not critical predictors of mental health service use. The truth is that a few caregivers are concerned about mental health issues in their children, even though mental health is a common problem in primary care (Sayal et al., 2010).

Caregivers find it difficult to recognise mental health issues in children and ascertaining the severity of the issue. They identified this as a barrier to help-seeking; another barrier was not being listened to by health professionals (Reardon et al., 2017). Godoy et al. (2014) claim that acknowledging and accepting caregivers' intuition regarding mental health issues and help-seeking could reduce unmet mental health needs of children. Therefore, understanding that caregivers play a vital role in adolescents' mental healthcare, and acknowledging caregivers as key supporters of adolescents, are critical (Chadda, 2014; Ambikile & Outwater, 2012).

Researchers insist that caregivers must be *aware of and recognise* mental health issues in adolescents if they are to assist adolescents through timely help-seeking. Furthermore, increasing caregivers' knowledge and skills regarding mental health issues may be positively related to their willingness to seek help. Healthcare professionals should consider caregivers' beliefs about and attitudes towards mental health issues, in order to overcome barriers and increase their efficacy in seeking advice (Steding, 2016; Thurston et al., 2016; Pavuluri et al., 1996). Consequently, caregivers' perceptions of mental health issues influence their management of and help-seeking for these adolescents (Kizaur, 2016; Adhikari et al., 2015; Dogra et al.,

2002). A better understanding of caregivers' influence on adolescent mental health outcomes (Godoy et al., 2014; Hoskins, 2014; Kieling et al., 2011) may create pathways to support them (Finan et al., 2018; Gavazzi, 2011) and improve their help-seeking, which could, in turn, prevent long-term adverse consequences (Skylstad et al., 2019; Abera et al., 2015; Hoskins, 2014).

Caregivers' multiple role responsibilities and general caregiving of adolescents may be challenging and time-consuming for the caregiver to manage. Doing so can lead to unmet needs in caregivers and their care recipients (Oruche et al., 2017; Chadda, 2014; Ambikile & Outwater, 2012). In summary, caregivers remain vital for adolescents' healthcare (Patton et al., 2016; Gavazzi, 2011; Evans et al., 2005), and they are in a unique position to judge adolescent behaviour (Hoskins, 2014; Talley et al., 2014; Manders et al., 2009). Caregivers act as gatekeepers for adolescents (Skylstad et al., 2019; Reardon et al., 2017), and it is crucial to understand their impact on adolescents with mental health issues (Hoskins, 2014). Caring for an adolescent with mental health issues can cause strain, and caregivers can experience several challenges that impact their well-being (National Alliance for Caregiving & AARP, 2009).

Distinguishing normal adolescent development from mental health issues is, thus, problematic (Paruk & Karim, 2016), especially for the caregiver in the social environment that involves family, school, and community influences (APA, 2002) (see Section 2.4.4.1). Societal values and beliefs influence views on mental health (Videbeck, 2020), and cultural differences regarding the acceptability of types of behaviour or mental health issues should be considered during information sessions (Halter, 2018).

### **2.4.3 Mental health issues and culture**

People must be mindful of the complexities of mental health issues in relation to culture. Each culture conceptualises a unique perception of mental health issues, which complicates the recognition of abnormal behaviour (Monteiro, 2015; Costello et al., 2006). Normative behaviour in one culture can be problematic in another (Monteiro, 2015; Stiffler & Dever, 2015), while acceptable behaviour in one culture

does not mean it is acceptable in another (Videbeck, 2020). Cultural beliefs about mental well-being and mental health issues, and their causes, can differ among populations (Halter, 2018; Naik & Kaneda, 2015; Patton et al., 2010; Lund C., 2008; Remschmidt & Belfer, 2005).

Videbeck (2020) and Halter (2018) explain that *cultural factors* influence people's beliefs about the causes of mental health issues and, in turn, affect individuals' understanding of factors responsible for the development of mental health issues. Knowledge about cultural patterns may help us to comprehend caregivers' misconceptions about mental health issues and their related indicators. A better understanding of how cultural context guides the caregiver in identifying mental health issues and help-seeking is required (Curtin et al., 2017; Abdulmalik & Thornicroft, 2016). This understanding could assist researchers to address the gap in caregivers' knowledge by educating them about the multiple risk factors implicated in mental health issues. Early identification of issues can prevent adverse adolescent mental health outcomes (Monteiro, 2015; Richardson & Wyatt, 2010), and support caregivers with information on mental health indicators.

#### **2.4.4 Indicators of mental health issues**

Various risk factors predispose people and contribute to the onset of mental health disorders, while protective factors lower the risk of or prevent the probability of someone developing a mental health disorder. *Risk and protective factors* include interrelated fields, such as social environment, personality, and behaviour (Jessor, 2016; NBHC, 2016; Nightingale & Fischhoff, 2001). Loeber et al. (2009) state that adolescents are even more prone to mental health issues if they are exposed to prevalent risk factors and minor protective factors. Wille et al. (2008) and Videbeck (2020) agree that adolescents who are subjected to higher risk factors might develop mental health issues.

Ogundele (2018) lists *common factors* that increase the risk of developing mental health issues, namely, poor socio-economic environment, poverty, gender, age, hostile family life, and contact with household tobacco use. Specific risk factors that have been widely documented for adolescents in South Africa are being exposed to

violence, poverty, abuse, loss, bullying, family disruption, upsetting life events and families affected by HIV and AIDS (Van Niekerk & Mathews, 2019; Flisher et al., 2012; Patel et al., 2007)

Mental health issues, if unrecognised, can render the adolescent vulnerable, and can contribute to the development of a mental health disorder in any context (Child Mind Institute, 2016; WHO, 2014; Blum et al., 2012; Fisher et al., 2011). Understanding *risk or protective factors* involved in adolescents' mental health can provide knowledge, so that caregiver practices and the development of prevention strategies can be targeted. Exposing adolescents to risk factors might increase the likelihood of them developing mental health disorders, and could influence the duration and severity of disorders (McAdam et al., 2018). A basic understanding of risk factors associated with mental health issues may help caregivers to act as change agents and promoters for the prevention of mental health issues in their immediate social environment.

#### 2.4.4.1 *Risk factors in the social environment*

According to Fisher et al. (2011), the family, education facilities, and the broader community forms the *social environment* that influences adolescent mental health. Evans et al. (2015) refer to individual, family, and community influences as risk domains. Loeber et al. (2009) and Scott et al. (2015) agree about similar domains and add peer groups as another influential factor. Another risk factor, suggested by Masare et al. (2017), is the school setting. Home and school environments can precipitate behavioural problems, which can lead to mental health issues (Ogundele, 2018; Olives et al., 2013).

Consequently, the relations and interactions between the adolescents, their families, and the wider community may affect adolescents. These impacts can either promote good mental health or indicate a high risk for poor mental health in adolescents. Transitions during adolescence may cause internal or external stresses for adolescents and their families (Anniko et al., 2019; Krapić et al., 2015; Dogra et al., 2002). These stresses could be multifactorial (McAdam et al., 2018; Pinto et al., 2014; Dwivedi & Harper, 2004), could create vulnerabilities in adolescents (Krapić et al., 2015; Nightingale & Fischhoff, 2001), and may contribute to poor mental health

(Swaminathan, 2016). Poor mental health in adolescents which is provoked by risk factors signifies the possibility of developing mental health issues (Masare et al., 2017; Patel et al., 2007). Examples of individual, family, school, and community indicators are the following.

- Individual factors include, for example, sleeping problems, inactivity, substance abuse, stress due to brain changes in adolescence (Michael & Jameson, 2017; Child Mind Institute, 2016; NBHC, 2016; Durlak, 1998), low self-esteem, and internalising and externalising behaviours (Pinto et al., 2014). Individual, multifactorial risk determinants responsible for mental health issues may vary between regions and nations (Vijayakumar et al., 2015).
- Family factors contributing to mental health issues are lack of family support, absence of caregivers from adolescents' lives and caregivers not being involved in adolescents' lives (Michael & Jameson, 2017; NBHC, 2016; Durlak, 1998), divorced or separated parents, and physical and sexual abuse (Pinto et al., 2014). Wille et al. (2008) and Georgiou and Symeou (2018) identified family conflict and parental strain as potent risk predictors for developing mental health issues. Less favourable circumstances relating to, for instance, parental support and resources, increase the likelihood of adolescents being vulnerable and developing mental health issues.
- School factors include academic challenges, bullying, rejection by peers, and lacking a sense of belonging (Michael & Jameson, 2017; NBHC, 2016; Vaz et al., 2015; Nightingale & Fischhoff, 2001). Furthermore, Pinto et al. (2014) identified "discrimination and racism", or being from a "low socioeconomic level" in a school environment as leading to mental health issues.
- Lastly, community factors are represented by exposure to violence, transport challenges, limited recreational activities or facilities, stigma related to mental issues, and inadequate mental health and support services (Michael & Jameson, 2017; NBHC, 2016). Psychosocial and religious aspects linked to the community's traditions and practices may also contribute to the development of mental health issues (Pinto et al., 2014).

These indicators illuminate global and local trends among adolescents but might be even more prominent in rural areas that lack knowledge, resources, and support concerning mental health issues.

#### 2.4.4.2 *Strategies to prevent risk factors*

Accumulation of risk factors should be prevented through effective strategies. Kieling et al. (2011) and Magai et al. (2018) assert that exposure to risk factors can increase the occurrence of mental health issues, and early identification may prevent chronic mental disorders. Kieling's review established that strategies that decrease risk factors and strengthen protective factors might prevent the onset of mental health disorders. Unrecognised and untreated mental health issues may culminate in adverse conditions and the development of chronic mental health disorders (WHO, 2014).

Strategies that reinforce protective factors have the potential to improve adolescents' mental health (NBHC, 2016; Scott et al., 2015; Wille et al., 2008). Generally speaking, there should be a focus on reducing risk factors and increasing protective factors (McAdam et al., 2018; Durlak, 1998). This interpretation differs from that of Rutter and Taylor (2008), who argue that strategies should focus on protective factors because it is more difficult to adapt or change risk factors. On the other hand, Patel et al. (2008a) believe that the principal focus on *prevention* will decrease the impact of risk factors. These multifactorial risk exposures have causal attributes to adolescents' mental health outcomes; thus, the importance of attempting to prevent it. In achieving this goal, it is necessary to involve caregivers as individuals responsible for adolescents, in preventive strategies (Robila, 2016; Kuhn & Laird, 2014; Hoagwood et al., 2010).

Caregivers are crucial partners in the prevention and promotion of adolescents' mental health (Patel et al., 2016; Robila, 2016). Supporting caregivers through targeted initiatives has the potential to reduce causal risk factors contributing to mental health issues (Scott et al., 2015). Empowering the caregivers and community through dissemination of relevant information related to adolescents' mental health may minimise potentially chronic conditions (Finan et al., 2018; Leventhal, 2018; Petersen et al., 2015). Wille et al. (2008) found that adequate resources at individual,

family, and community levels related to a diminished incidence of mental health issues. Consequently, caregivers play a critical role in adolescent mental health outcomes and well-being (Gavazzi, 2011; APA, 2002).

The abovementioned illustrates the reality of caregivers' situations within family settings in South Africa and raises awareness of the caregivers' context when caring for adolescents with mental health issues. Prioritising caregiver support may lead the way to reduce the burden of poor mental health in adolescents.

## **2.5 THE PREVALENCE OF ADOLESCENT MENTAL HEALTH ISSUES**

There were 1.2 billion youth aged 15-24 years globally in 2019, of which 211 million lived in sub-Saharan Africa (United Nations, 2019). The number of the youth population has stabilised in Latin America, the Caribbean, Europe, North America and Oceania. In contrast, the youth population in Asia and Africa has undergone significant changes in numbers (United Nations Department of Economic and Social Affairs Population Division, 2015). The vast majority of adolescents aged 10-19 years live in LMICs and comprise 16.4% of the world's population (WHO, 2014). Sub-Saharan Africa's youth population will peak by 2050 and is predicted to have increased by 89% by this time (United Nations, 2019).

This expected increase in the adolescent population in LMICs implies a corresponding increase in the prevalence of mental health disorders because nearly half of all lifelong mental health disorders start by age 14 (Kassebaum et al., 2017; Atilola, 2015; Scott et al., 2015). Worldwide, prevalence rates of mental health disorders are about 10%-20% in children and adolescents (Malhotra & Patra, 2014; Patel et al., 2008; Patel et al., 2007). Mental health prevalence statistics for adolescents are very scarce, and Erskine et al. (2017) reported limited availability of data on the prevalence among adolescent. These authors found that 124 of 187 countries had no data on any mental health disorder of children between 5 and 17 years.

It is cause for concern that sub-Saharan Africa reports only 2% of children suffering from mental health disorders, indicating limited statistics relating to mental health disorders in adolescents (Erskine et al., 2017). Adolescents under the age of 18

years make up approximately 40% of the South African population, and this high proportion is likely to contribute to a higher mental health issue prevalence (Scott et al., 2015). Not only are mental health issues of children and adolescents increasing, but there are no clear policy guidelines for services to ensure the mental health of children and adolescents in South Africa. All nine provinces in South Africa provide general primary healthcare services and focus on HIV and AIDS, tuberculosis, and maternal and child health, however, limited provision is made to promote mental health (Mokitimi et al., 2018). Atilola (2015) refers to the neglect of development policy concerning the mental health of children and adolescents in LMICs. Mental health promotion should be prioritised in public health, in light of the burden caused by mental health issues (Monteiro, 2015; WHO, 2014).

In light of these shortcomings, Skylstad et al. (2019) draw our attention to ineffective mental health service provision and fragmented mental healthcare for children and adolescents. They highlight the necessity of informing stakeholders (caregivers and the community) that they should be cognisant of adolescents' mental health because failure to detect it early on could have severe consequences. We should understand the extent of the mental health burden on adolescents to comprehend the impact on caregivers.

## **2.6 IMPACT ON CAREGIVERS' CARING FOR ADOLESCENTS WITH MENTAL HEALTH ISSUES**

Caregivers carry a double burden of disease, that is, that of the adolescent in their care, as well as their own emotional burden (Stacey et al., 2016). Caregivers struggle to cope with adolescents' mental health issues and experience a great deal of stress. Caregivers' supposed "labour of love" causes physical, emotional, social, and financial turmoil.

Caregiver burdens are well documented (NYC Department of Aging, 2017; Talley et al., 2014; Marimbe-Dube, 2013; Ambikile & Outwater, 2012; Mendenhall & Mount, 2011; Pramita & Jena, 2011; Mavundla et al., 2009; Schor, 2003), and is a theme that has been explored often over the past few decades. However, a satisfying definition of caregiver burden has still not been conceptualised. The negative impact

of the caregiving role of family members is conveniently used by researchers to explain the concept of caregiver burden (Ofosu, 2017; Bastawrous, 2013). Mendenhall and Mount (2011) describe the caregiver burden as a challenging situation that involves significant responsibilities and role unfamiliarity, and which increases stress levels.

### **2.6.1 Caregiver burden**

The caregiver burden can be divided into two components, namely, objective and subjective burdens. Objective burdens (time, financial strain, and daily routine disruptions) involve observable effects that are inconvenient and difficult to manage. In contrast, subjective burden refers to the caregiver's emotional state (negative feelings or perceptions) associated with caregiving (Ofosu, 2017; Flyckt et al., 2015; Talley et al., 2014). Objective burdens are sometimes easier for caregivers to manage, because of their tangibility, whereas a subjective perception can create distress that is more emotional and may be challenging to grasp (Gérain & Zech, 2019).

Living with children and adolescents with mental health issues has been found to be emotionally, socially, physically, and financially burdensome to caregivers (Ae-Ngibise et al., 2015; Ambikile & Outwater, 2012), and caregivers suffer from high levels of burden (Talley et al., 2014; Ambikile & Outwater, 2012; Dada et al., 2011). Ambikile and Outwater (2012). Mendenhall and Mount (2011) claim that caring for children and adolescents with mental health issues cause additional burdens, which increase caregivers' stress levels further. Caregivers experience significant levels of burdens, including financial and emotional hardships, and even stigma related to mental health issues (Abdulmalik & Thornicroft, 2016; Oruche et al., 2012; Dada et al., 2011).

- *Emotional burden* includes feelings of sadness, concern, or “hurting inside” due to caregiving responsibilities (Ambikile & Outwater, 2012; Oruche et al., 2012; Knock et al., 2011). Other emotional strain endured by caregivers is anxiety and stress (Mwei, 2015; Talley et al., 2014; Mendenhall & Mount, 2011; Wynaden et al., 2006). Participants in a Kenyan study by Molebatsi et

al. (2017) mentioned that constant worry about care recipients' condition caused emotional pain. Caregivers in Zimbabwe used the concept of "thinking too much" to describe their emotional burden (Marimbe et al., 2016). Caregivers in the study by Knock et al. (2011) commonly mentioned demands on everyday activities, as well as emotional burdens. Female caregivers experienced higher distress and more severe burdens than men did (Molebatsi et al., 2017; Viana et al., 2013; Ambikile & Outwater, 2012).

- Furthermore, *social burdens* are represented by disruption of family relationships and social life by care responsibilities, which constrain personal time or cause shame about care recipients' mental health issues (Mwei, 2015; Oruche et al., 2012; Mendenhall & Mount, 2011; Pramita & Jena, 2011). The possibility of rejection by the community due to the stigma about mental health issues (Marimbe et al., 2016; Oruche et al., 2012) could lead to social isolation. Caregivers also receive inadequate social support, probably triggered by poor public awareness regarding mental health issues (Ambikile & Outwater, 2012).
- *Physical burden* is brought about by fatigue, stress, and sleep disturbances (Marimbe et al., 2016; Oruche et al., 2012; Mendenhall & Mount, 2011; Mavundla et al., 2009). Some research participants in Zimbabwe complained of physical symptoms such as back pain and high blood pressure (Marimbe et al., 2016). However, in a study in South Africa, researchers found that Black African and Coloured<sup>4</sup> caregivers reported less physical burden than other caregivers (Yakubu & Schutte, 2018).
- Extra expenditure related to care recipients' conditions added to the *economic burden* for caregivers. Some financial challenges reported in the literature relate to caregivers from a poor socio-economic setting who struggle with transport expenses, loss of income, employment challenges, high childcare expenses, and daily living expenses (Molebatsi et al., 2017; Viana et al., 2013; Ambikile & Outwater, 2012; Pramita & Jena, 2011). Limited financial

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<sup>4</sup> In Southern Africa, the term Coloured has a specialised meaning in that it denotes a person of mixed racial ancestry.

resources contribute to the burden of already poor caregivers (Mwei, 2015; Talley et al., 2014; Knock et al., 2011). Additionally, uncontrollable financial circumstances were more challenging to caregivers than subjective burdens were (Ofosu, 2017). On the other hand, primarily Black and Coloured caregivers in a low-income setting indicated minimal financial burden, according to Yakubu and Schutte (2018).

Other burdens mentioned are caregivers' incapacity to care for themselves and sustaining their marital relationships (Oruche et al., 2012). Caregivers are also burdened by other difficulties, such as adolescents' negative behaviour and own parenting practices. Dividing their attention between the care recipient and other children in the same household cause caregivers distress. Even more difficult for the caregiver to manage is the developmental issues of the adolescent (Knock et al., 2011).

Bastawrous (2013) highlights that caregiver burden stems from role conflict and role strain, especially among female caregivers. Caregivers caring for their own children (43%), versus a relative's children (29%), experienced higher stress levels (National Alliance for Caregiving & AARP, 2009). High unemployment, low literacy, and older women often represent the typical caregiver traits in a multi-generational South African context. This typology can predict the contextual influences of the current research study. Therefore, the importance of understanding caregiver burden is vital for supporting them and identifying the needs related to these worrying challenges. Recognising and addressing caregivers' specific needs may supply appropriate resources through effective initiatives that may strengthen caregiving behaviour (Molebatsi et al., 2017; Atilola, 2015; Meltzer et al., 2011). There is a connection between caregiver burden and well-being, and it affects the caregiving relationship either positively or negatively.

### **2.6.2 Caregiver well-being**

The well-being of caregivers caring for adolescents with mental health issues is critical. The caregivers are a fundamental source of support for adolescents and have the potential to regulate adolescent behaviour more positively. Additionally,

caregivers have a crucial role to play in laying the foundations for optimal mental health for adolescents and, hence, it is essential to attend to their well-being (WHO et al., 2018; WHO, 2017). Brown and Brown (2014) report that research studies tend to focus more on the negative aspects of caregiving. Caregivers do not always experience caregiving negatively, and they found a positive relation between caregiving and well-being. Caregivers were satisfied with their caregiver role and demonstrated positive feelings of compassion and closeness towards care recipients.

Well-being is also prioritised under the Sustainable Developmental Goals adopted by the United Nations in 2015. Goal No. 3 focuses on healthy lives and promoting well-being for people of all ages, including their mental health (United Nations Department of Economic and Social Affairs Population Division, 2015). Caregiver well-being is also essential in the caregiver-adolescent dyad relationship, and caregivers need a caring platform to ventilate their frustrations (Stavrou et al., 2017). It can be said that providing caregivers with support opportunities may boost their well-being (Balestrery et al., 2015). Support platforms may improve their caregiving abilities and coping skills, thereby producing a boost to their well-being (Aschbrenner et al., 2010). Nonetheless, understanding caregivers' well-being is inherently linked to the type of support they need to achieve that state of well-being.

## **2.7 CAREGIVERS' UNMET NEEDS AND SUPPORT CHALLENGES**

Enhancement of caregiver well-being, as well as that of their children and families, can transpire through addressing several *unmet support needs* and challenges (Oruche et al., 2012). A wide range of caregiver support needs have been documented in the literature, including informational needs (Ford et al., 2016; Pelentsov et al., 2015; Talley et al., 2014), training needs (Bingham, 2017; Kadungure, 2017; Talley et al., 2014), need for professional assistance (Chadda, 2014), need for social support (Mikolajczak et al., 2019; Reardon et al., 2017; Pelentsov et al., 2015; Talley et al., 2014), need for emotional support (Steding, 2016; Talley et al., 2014; Logsdon & Robinson, 2000), spiritual needs (Pelentsov et al., 2015; Talley et al., 2014) and financial needs (Huus et al., 2017; Sukeri et al., 2017; Talley et al., 2014). Caregivers' needs must be adequately addressed to

ensure successful caregiving (Whitlatch & Orsulic-Jeras, 2018; Stavrou et al., 2017; Deeken et al., 2003). Sukeri et al. (2017) agree with the abovementioned analysis and add the caregivers' need for community services. To support and maintain their caregiving, it is essential to thoroughly evaluate the needs, strengths, and choices of caregivers (Feinberg & Houser, 2012).

### **2.7.1 Information needs**

Adolescents' development and the caregivers' role in adolescents' health promotion are multifaceted. Caregivers are, overall, interested in receiving information concerning health issues, primarily information related to adolescents. Caregivers need relevant information that can assist them by creating awareness and increasing their knowledge and recognition of mental health issues in adolescents (Gronholm et al., 2015; Mendenhall & Frauenholtz, 2013; National Alliance for Caregiving & AARP, 2009; Logsdon & Robinson, 2000). Remarkably, Ford et al. (2016) found that Black caregivers (a minority population) were more interested in acquiring health information (including information on mental health) than White caregivers. This study investigated parents' and adolescents' interest in receiving health communication information in primary care settings, on 18 topics, including mental health.

Malaysian caregivers from a lower income group ultimately reported a need for information about children (<18 years) with different types of disabilities in a study by Suriati et al. (2011). Information needs identified were, among others, to know about managing the child's behaviour, about the condition itself, and services available.

Information needs differ among caregivers, depending on their characteristics and circumstances. Knock et al. (2011) report on difficulties faced by caregivers of adolescents on the schizophrenia spectrum. They found insufficient and poor quality information about the adolescents' condition and treatment. Providing necessary information regarding mental health issues may raise rural caregivers' awareness and assist them with decision-making (Fenell & Hovestadt, 2005). Beyond information, training regarding adolescence and mental health issues can also supply valuable support for their caregiving practices.

### **2.7.2 Training needs**

Caregivers need training and skills development in active adolescent support (Cavaleri et al., 2011). Untrained caregivers could mistake mental health issues as possible developmental issues related to adolescence, and neglect getting access to health services (Thurston et al., 2016). Caregiver *training* can alleviate adverse outcomes for both themselves and adolescents (Whitlatch & Orsulic-Jeras, 2018; Jalling, 2017), thereby inherently promoting mental health. In her study, Steding (2016) reasons that caregivers have not received adequate training to recognise problematic behaviour that creates barriers to help-seeking from healthcare providers or services. Proficient caregiving could be achieved through better guidance and training of caregivers (Bingham, 2017; Talley et al., 2014; Logsdon & Robinson, 2000). Talley et al. (2014) highlight caregivers' need for training and skills development to manage mental health issues in adolescents.

Skill development gives caregivers confidence and prepares them to deliver caregiving activities (Henning-Smith & Lahr, 2018). Developing caregivers' skills matters because caregivers who received training and information relating to recognising mental health issues, may seek help timeously (Thurston et al., 2016). Supporting skills development was identified as a common supportive need (Cavaleri et al., 2011) among caregivers. It is in this regard that healthcare professionals can offer the necessary support by providing information and training to this invisible group of informal helpers in resource-restrained communities.

### **2.7.3 Need for professional assistance**

Caregivers are in desperate need of assistance from healthcare professionals and services. They struggle to cope, and experience loss of control owing to problematic behaviour by adolescents. Too often, caregivers seek professional help that appears to fail to provide support (Choate, 2015). Caregivers need help from healthcare professionals, to educate and train them (Ford et al., 2016). According to Dixe et al. (2019), nurses are the professionals from which caregivers prefer to receive information.

Healthcare providers should concentrate more on caregivers' needs (Chadda, 2014). Sintayehu et al. (2015) report that female, rural, and uneducated caregivers who look after care recipients who are at risk of developing mental health issues need more attention. Rural caregivers of children with special needs experienced higher dissatisfaction with health services, or the lack thereof (Denby & Bowmer, 2013). Another viewpoint of caregivers was that they lacked access to competent healthcare professionals who understood the healthcare needs of children (Suriati et al., 2011), especially in rural communities (Brazil et al., 2014) that had limited support networks.

#### **2.7.4 Support network needs**

A strong support network can alleviate the caregiving burden and reduce unmet needs (Huus et al., 2017; Fernandes & Angelo, 2016), thereby achieving a better sense of well-being in caregivers (Letvak, 2002). Caregivers endure isolation due to stigmatising views related to care recipients' conditions (Lushin & O'Brien, 2016), and long for support from family and friends in these stressful caregiving situations. However, family support is not always seen as useful or desirable, because caregivers do not want to burden the family, or because caregivers are embarrassed (Choate, 2015; Kuhn & Laird, 2014).

In this light, Hoagwood et al. (2010) argue that the family can be a source of support, especially when caregivers experience shame or are the recipients of negativity from the community. These authors provide evidence that *support networks* can reduce caregiver burden, though research by McDonald et al. (1996) on caregiver stress states that support interventions should not replace family or relative support in caring for children. Thoits (2010) defines social support as informational, practical, or emotional assistance from various family members, friends, or peers. She states that social support could lessen the impact of stress on caregivers' well-being. Support networks determine the emotional well-being of caregivers and make them feel cherished.

### **2.7.5 Emotional needs**

Emotional or psychological needs relate to subjective feelings of what caregivers require to improve their well-being (Kim et al., 2017; Chien & Lee, 2013). An understanding of caregivers' emotional needs could assist in determining the support they need. Powerlessness and negative feelings cause emotional discomfort in caregivers (Steding, 2016; Choate, 2015; Grobler & Roos, 2014; Logsdon & Robinson, 2000). Emotional well-being impacts caregivers' quality of life (Kim et al., 2017) and, therefore, support to caregivers can minimise stressors. Stressors and anxiety are seen as psychological factors that impact an individual's perception of well-being, implying higher burdens (Toledano-Toledano & Domínguez-Guedea, 2019). King et al. (1999) also mention being worried, depressed, and strained as variables of emotional well-being in parents, while Koerting et al. (2013) also mention fear.

Caring for children caused substantially more stress than caring for other family members (Reardon et al., 2017; Penning & Wu, 2016). Lee et al. (2016) conclude that parental stress results from children's behavioural problems, which influence parents' emotional well-being, while Tomlinson (2013) claims that caregivers of children with emotional and behavioural issues experience high stress levels. Thus, it is important to ensure caregiver well-being by providing *emotional* support, especially in resource-constrained environments. Caregivers perceive support as essential for improving their self-worth, self-efficacy, and coping behaviour (Gupta et al., 2015). The rationale for addressing caregivers' emotional needs is to reduce burdens, enhance their well-being, and eliminate stressors. Emotional needs can be addressed through community support as well as spirituality and religious activities (Grobler & Roos, 2014; Talley et al., 2014).

### **2.7.6 Spiritual needs**

The caregiving role is also associated with spiritual needs (Talley et al., 2014; Sawatzky & Fowler-Kerry, 2003). Some families mentioned a lack of support from faith-based organisations in a study conducted in Ghana. Certain mothers felt that prayers and attending church activities helped them to cope better and to care for

their child with an intellectual disability (Oti-Boadi, 2017). Scharlach et al. (2001) investigated caregivers' spiritual needs and found that African American caregivers tap into faith-based support to mitigate their stress, whereas Talley et al. (2014) similarly found that African American caregivers suffered less burden and emotional distress because of attending religious or church activities. Schor (2003) state that families involved in religious activities ameliorate adolescents' risky behaviours, such as substance use. Faith-based organisations could provide support networks to vulnerable families in rural communities (Berry & Malek, 2017).

Pelentsov et al. (2015) found that parents reported on *spiritual needs*, such as a crisis of faith and questions about their spirituality, and tried to make sense and meaning of the circumstances. Religious beliefs assist in coping with caregivers' well-being (Sawatzky & Fowler-Kerry, 2003), as does attending church support groups (Letvak, 2002). Faith-based organisations in communities could be a cost-effective way to support caregivers.

Traditionally, rural communities tend to rely more on culture and religion to deal with stressors. Partnerships with faith-based groups could provide education and training to caregivers through support groups (Talley et al., 2014). The broader community, including teachers, regional and faith leaders, could intervene with supportive initiatives relevant to community needs (Zuurmond et al., 2019). Caregiving is stressful (Penning & Wu, 2016) and is compounded further by financial burdens (Huus et al., 2017; Talley et al., 2014; Suriati et al., 2011) in resource-constrained environments.

### **2.7.7 Financial needs**

Economic challenges, such as transport costs, could occur due to poverty and unemployment, which is ubiquitous to South Africa (Burger & Christian, 2018; Christian, 2017; Greeff & Nolting, 2013; Mavundla et al., 2009). Indeed, Henning-Smith and Lahr (2018) describe the core challenges of rural caregivers that cause financial burdens, namely, transportation and access to resources. Rural caregivers in Australia also experienced stress associated with financial difficulties (Hussain et al., 2018). Caregivers may feel overwhelmed by financial challenges (Sukeri et al.,

2017), and this affects their quality of life (Deeken et al., 2003). Acknowledging caregivers' financial needs is fundamental (Buckner & Yeandle, 2015; Suriati et al., 2011).

The degree to which caregivers perceive their needs being unmet should not be ignored. Given these various unmet needs, targeted initiatives should be developed to support caregivers, to improve their well-being and quality of life.

## **2.8 TARGETED INITIATIVES FOR CAREGIVERS**

It is vital to develop appropriate and ongoing initiatives to support caregivers optimally by understanding and targeting their individual needs (Montgomery & Kosloski, 2009; Taylor-Richardson et al., 2006). Supporting the unmet needs of caregivers, like pillars in a healthcare environment (Brown & Brown, 2014), may strengthen their caregiving behaviour, subsequently developing better coping skills and improving the family's well-being (Stavrou et al., 2017; Talley et al., 2014; Oruche et al., 2012). Suitable initiatives, together with community awareness and support, may assist caregivers in their caregiving activities (Chang et al., 2016; Bastawrous & Armstrong, 2013). Altogether, support initiatives that provide training, information, and emotional resources to caregivers in their settings are imperative for effective caregiving. These authors propose, furthermore, involvement by local government or faith-based organisations to support caregivers. Forming community partnerships with vital stakeholders, families, and policymakers is a valuable resolution (Vining, 2019). Useful initiatives may promote emotional health and reduce the caregiving burden (Lahr & Henning-Smith, 2018). Supporting caregivers through ongoing practical, tailored initiatives may alter their stress levels during caretaking. It may be worthwhile in the long run.

Initiatives targeted at caregivers should take into account various elements, including age group, racial, and socio-economic background (Lahr & Henning-Smith, 2018; Talley et al., 2014; National Alliance for Caregiving & AARP, 2009). Vining (2019) states that support initiatives for addressing the needs of caregivers should be culturally congruent. Contextualised initiatives could advise policymakers and contribute to evidence-based practice. Moreover, initiatives that are designed ought

to be analytical and detailed, to ensure that both caregivers and care recipients reap the benefit thereof (Van Houtven et al., 2011).

Researchers should be mindful of caregivers with actual needs by reforming planned initiatives to deliver support and resources (Brown & Brown, 2014), thereby also boosting their self-efficacy, attitudes, skills, and coping mechanisms (Isa et al., 2016; Abera et al., 2015; Kate et al., 2013; Olin et al., 2010). Ongoing support through effective initiatives may reduce caregiver stress (Sintayehu et al., 2015) and increase their well-being (Corralejo & Rodríguez, 2018; Tarver et al., 2014). Others authors maintain that designing applicable caregiver initiatives in low-income and resource-constrained environments may lend support and access to relevant education needs (Healy et al., 2018; Tilahun et al., 2016; Forehand et al., 2014)

One other point to note is that initiatives with caregiver elements that equip them with skills, information, support networks, and efficient caregiving behaviour are essential in the prevention of mental health issues (Corralejo & Rodríguez, 2018; Bingham, 2017; Epstein et al., 2015; Tarver et al., 2014).

Some studies emphasise that resourceful initiatives should be commonly available at low cost, to empower caregivers by strengthening their abilities and eradicating mental health issues (Patel et al., 2008; Saraceno et al., 2007). Initiatives to support caregivers require transformation, to empower families, communities, schools, leaders, and policymakers by changing negative attitudes related to adolescent mental health (WHO, 2014; Flisher et al., 2012; Patel et al., 2008). Healthcare systems are challenged by a lack of resources, but still have an undeniable role to play in supporting the public.

The burdened healthcare system needs to empower the public and communities to deliver healthcare through information communication technology (ICT) initiatives (Royston et al., 2015; Telenor Group, 2012). Healthcare services and information are now readily available to anyone, anywhere, and at any time (Aceto et al., 2018; Negash et al., 2018; Genz et al., 2015) through communication technologies. Communication technologies do not only have the potential to deliver healthcare services, information, and treatment (Negash et al., 2018), but can boost the individual's well-being and quality of life (Ellery & Ellery, 2012).

## **2.9 CHAPTER SUMMARY**

This literature chapter introduced discussions on a number of key issues that are essential for laying a foundation to understand the caregiver and care recipient context. The chapter, furthermore, reviewed concepts related to caregivers and established general caregiver characteristics. The profile and prevalence of South African caregivers were outlined. Adolescents with mental health issues, as care-recipients, related concepts, caregivers and cultural roles in the context of mental health issues were explored. The discussions proceeded to explain mental health indicators, risk factors and prevention of risk factors, as well as the prevalence of mental health issues in adolescents. It was clearly pointed out that caring for adolescents with mental health issues impacted the caregiver, including increasing the burden on the caregiver and affecting the caregiver's well-being negatively, which lead to caregivers experiencing various unmet needs. The information in this chapter will serve to guide our understanding in the investigation into the need for initiatives targeted to caregivers, especially those from rural areas. Chapter 3 will continue to explore literature related to caregiver initiatives, by addressing communication technologies, with the focus on mobile health (mHealth).

## **CHAPTER 3: LITERATURE REVIEW: MOBILE HEALTH COMMUNICATION TECHNOLOGY AND THE CAREGIVERS OF ADOLESCENTS WITH MENTAL HEALTH ISSUES**

*“The problems are solved, not by giving new information, but by arranging what we have known since long.”*

*-Ludwig Wittgenstein<sup>5</sup>-*

### **3.1 INTRODUCTION**

This chapter presents the results of a literature search done via various scholarly databases. The researcher relied on this vast selection of sources related to communication technologies in order to provide a coherent synthesis that could serve as a foundation for the study. This literature review aims to position research presented in Chapters 4, 5 and 6, which will inform the overall aim of the study. In this section, the researcher explores communication technology and its potential to support rural caregivers by explaining the communication technology landscape and associated eHealth milieu. Then, a description of the mHealth landscape follows, which focusses on mHealth characteristics and its relation to caregiving. It is important to take note of the benefits and barriers of mHealth initiatives as a way to support caregivers of adolescents with mental health issues living in a rural area. Keeping the potential benefits and barriers in mind, the focus is on caregivers' readiness to adopt mHealth initiatives as a support tool. An understanding of the relevant legislation, both internationally and locally, was judged to be a necessary part of the discussion of this topic. Finally, mobile phone technology is explored, as a vehicle for caregivers to use messaging, call services and mobile applications.

### **3.2 INITIATING COMMUNICATION TECHNOLOGY AS SUPPORT TO CAREGIVERS OF ADOLESCENTS WITH MENTAL HEALTH ISSUES**

Communication technology as a support initiative can transform healthcare by addressing various healthcare problems through appropriate applications of technology in information dissemination, information access, or assisting in decision-

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<sup>5</sup> <https://libquotes.com/ludwig-wittgenstein/quote/lbu9n2k>

making (Marin et al., 2017; Delponte et al., 2015; Avgar et al., 2012; Danis et al., 2010). The last two decades distinguished themselves as the so-called information age (Aceto et al., 2018; Farrell & McKinnon, 2003), and the commencement of the fourth industrial revolution (Lee et al., 2018; Schwab, 2015), through which access to information proliferated through digital distribution (Ellery & Ellery, 2012; Eysenbach & Jadad, 2001).

### **3.2.1 The communication technology landscape**

Communication technology can distribute, gather, generate, communicate, and process information electronically through the Internet, using different devices, including computers, handheld devices, cellular phones, cable TV, tablets, and other wireless devices (David, 2015; Hollis et al., 2015; Free et al., 2013). Communication technology that provides support and information is divided into traditional and modern technologies. Traditional technologies include radio, television, and landline telephones, while modern technologies include computers, mobile phones and the Internet (Hemmat et al., 2017; Davis et al., 2016; Delponte et al., 2015).

Hilty et al. (2017) explain the diversification of communication technology terminology further, by including examples of terms like Internet-based, online, telehealth, e-mental health, web-based and digital health. Oldenburg et al. (2015) use the term digital communications to refer to the use of several devices and platforms to integrate text, photos, videos, 3-D images, and virtual reality. Digital communication technologies for healthcare (*digital health*) originated from electronic healthcare (*eHealth*), of which mobile healthcare (*mHealth*), also called wireless health, is a subdivision (Istepanian & Woodward, 2017; Michael et al., 2012; Mehregany & Saldivar, 2012). Healthcare services provided through mHealth and eHealth, consist of hardware, software, media, and networks to collect, communicate and present information via calls, data, messages, images, and text (Marin et al., 2017; Delponte et al., 2015; Källander et al., 2013; Källander, 2010).

Rigby and Ammenwerth (2016) claim that communication technology could, however, be detrimental to consumers and is not without harmful consequences. They go as far as implying that health communication technologies can cause direct

harm because of inept or inadequate health systems. Indeed, the researcher's own opinion is that communication technology can be risky for consumers, especially when there is inadequate quality assurance of the content displayed or distributed. The sustainability of communication technology might be harmful to consumers in the absence of collaboration between relevant official stakeholders, who should ensure the implementation and maintenance of communication technology. For instance, the European Commission (2014) raised concerns in their Green Paper regarding the transparency of information available on some mHealth solutions.

Martin-Sanchez and Aguiar-Pulido (2017) reason that communication technology should be operative, dependable, and easy to use, mainly in underserved populations that face some challenges relating to equity, cultural issues, and language barriers to communication technology use. The argument of Mesko et al. (2017) convinced the researcher that we need to know more about the importance of the sustainability of communication technology, considering the rigid regulations, stakeholder resistance to change, and disregard of the human factor by digital health, which could transform culture. Providing healthcare through technologies should include improving digital literacy; otherwise, consumers might experience problems using electronic devices in the "jungle" of electronic healthcare information.

### **3.2.2 eHealth milieu**

Aceto et al. (2018), the Registered Nurses' Association of Ontario (2017), and Pagliari et al. (2005) all define *eHealth* as using electronic information and communication applications for healthcare. After a scoping review, Pagliari et al. (2005), furthermore, distinguishes broad variations in eHealth definitions. In their review, these authors mapped eHealth classifications according to functionality, contexts, participants, and theoretical issues. Concepts covered in this review are that eHealth targets decision-making, support, and health information to consumers. eHealth is linked mainly to operational communication, through digital technologies (the Internet).

The WHO (2016b) declares that *eHealth* is an industrial ICT application for providing healthcare services, health education, and knowledge, among other activities, to

support healthcare. Kreps et al. (2008) discuss the remarkable qualities of eHealth to transform healthcare communication through interaction, media content and contextualising, and personalising configurations to reach diverse populations.

Leading authors, Eysenbach and Jadad (2001), declare that providing a clear definition of *eHealth* is difficult, although some comprehensive definitions appear in the literature. They suggest the following definition of eHealth on page 2:

*e-health is an emerging field in the intersection of medical informatics, public health, and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology.*

Furthermore, they point out that the “e” in eHealth signifies more than electronic, but refers to 10 characteristics of eHealth: efficient, enhances quality, evidenced-based, empowers, encourages, educates, enables, extends, ethical, and equity. They also add easy to use, entertaining, and exciting to this extensive list. Eysenbach and Jadad’s definition of e-Health is instrumental and descriptive enough, according to the researcher.

Amalgamated electronic and personal communication can promote better public health outcomes by revolutionising healthcare for underserved and disadvantaged populations (Perrino et al., 2018; Neuhauser & Kreps, 2011). Adapting eHealth to individual information preferences, demographics, and health qualities is upcoming in LMIC’s status quo of healthcare (Neuhauser & Kreps, 2011). Digital technologies, inclusive of eHealth and mHealth, continue to transform and scale-up healthcare. Shifting from eHealth to mHealth can strengthen healthcare delivery by producing customised initiatives that support and empower communities (World Bank Group & WHO, 2016; Källander, 2010). With this in mind, and due to its popularity, the researcher was motivated to explore mHealth as a possible initiative to support caregivers in rural environments.

### 3.3 THE MHEALTH TECHNOLOGY LANDSCAPE

Providing healthcare through mobile technologies has become popular in all corners of the world, even among the poorest people (Aceto et al., 2018; Delponte et al., 2015; Akter & Ray, 2010). *mHealth* emerged from eHealth, as a unique solution to facilitate healthcare, service delivery, and information about health problems to the public, across the board (Davis et al., 2016; Källander, 2010). According to Malvey and Slovensky (2014), mHealth has four possible functions in healthcare; that is, health prevention, observation, treatment, and support. These functions pertain to health awareness, assessment of diseases, and care delivery, along with supporting the care recipient and the caregiver.

The broad penetration of mobile phones into all income-level homes has led to a remarkable evolution in healthcare delivery (Delponte et al., 2015), coupled with burgeoning research into healthcare technologies connected to low-income settings – this research is taking hold in developing countries (Chand et al., 2016; Chib et al., 2014; Mechael et al., 2012; Chigona et al., 2011). When it comes to this life-changing initiative, most researchers agree with the technological breakthroughs reported in research studies about the role of mHealth in healthcare.

There is a degree of uncertainty about the definition of *mHealth*, and the researcher believes it is necessary to report different perspectives to clarify the concept. Istepanian (1999) and Istepanian and Lacal (2003) were the first to invent and define the term mHealth. According to this definition, mHealth is wireless eHealth, which offers accessible healthcare through mobile communications and multimedia technologies. Likewise, Mechael et al. (2012) claim that mHealth is a subset of eHealth, whereby health services are delivered through mobile devices and, furthermore, enables anyone, at any time, to access healthcare for advice and information through an interactive process employing mobile technologies (Akter & Ray, 2010).

Whereas the abovementioned authors provide sufficient examples of mHealth definitions, the opinions of Davis et al. (2016) and the WHO (2011) regarding definitions of mHealth are in conflict with those of these authors. Davis et al. (2016) declare that similar definitions of mHealth occur in literature, and, in a report in 2011,

the WHO indicates that no standard mHealth definition has proven to be up to date; at the same time, the WHO states that mHealth is an element of eHealth. The researcher disagrees with these views claiming that no clear definition of mHealth exists. Instead, she endorses the definition Istepanian provided almost eight years earlier than the WHO, and 13 years before Davis et al. However, we should note that modernisation of technology over the years might affect the definition of mHealth, such as adapting technology-related terms to match current trends.

### **3.3.1 Characteristics of mHealth technology in healthcare**

The popularity of mHealth practices in healthcare has increased globally, and it influences individual, community and provincial health behaviour and health outcomes (Bishwajit & Dawah, 2014; Hall et al., 2014; Kahn et al., 2010). Initially, the creation of mHealth technologies for healthcare transpired mostly in high-income countries, although, today, mHealth infiltration in LMICs surpasses that of their more affluent counterparts. Severe limitations faced by LMICs, attributable to disease burdens, weak economies, inadequate infrastructure and shortcomings in human and physical resources could affect mHealth development (Malvey & Slovensky, 2017; Bastawrous & Armstrong, 2013; Malvey & Slovensky, 2014). The European Commission (2014) reports that mHealth services in Africa and Asia concentrate predominantly on advancing the effectiveness of healthcare systems and labour forces. In South Africa, a more important benefit is gained from mHealth messaging in disease prevention and awareness.

Employing mHealth technology in healthcare systems is emergent among researchers, and its use continues to increase, mainly in the public health sector. The focus of mHealth initiatives in public health is on health prevention and promotion, rather than disease management (Varshney, 2014; Chigona et al., 2011). Some other uses of mHealth technologies are appointment reminders, sending test results, assisting with decision-making, data collection, communication between healthcare professionals and care recipients, disease self-management, encouraging treatment adherence, providing information and education, and clinical management (Kabashiki, 2015; Hall et al., 2014; Free et al., 2013; Kumar et al., 2013). Furthermore, Labrique et al. (2013) report general supplemental mHealth

applications, namely, maintaining electronic health records, doing behaviour change communication, and training and educating care providers. mHealth technologies deliver ongoing healthcare support to individuals, including the caregiver population, through customised initiatives as required (Free et al., 2013; Kumar et al., 2013).

Given these explanations, the researcher believes that mHealth have demonstrated the necessary qualities and prospects to appropriately support the individual caregiver with information, education, training and behaviour modification, to guide decision-making, and communicate with healthcare professionals. Anderson-Lewis et al. (2018) propose that *mHealth technologies* could address caregivers' needs through customising health information according to their individual preferences. They also determined the value of mHealth technologies for under-resourced communities, by minimising health disparities. The popular and flexible technological abilities of mHealth underscore its suitability in supporting individuals, including caregivers (Free et al., 2013) in caregiving practices.

### **3.3.2 mHealth and caregiving**

We have seen a shift, from traditional healthcare to modern healthcare, in which face-to-face interventions have been replaced by available technology. mHealth technologies are moving out of traditional paradigms, thereby complementing the modernisation of the era. Modern healthcare represents health equity through reciprocal information transfer between healthcare professionals, care-recipients, family members, and caregivers (National Academies of Sciences, Engineering, 2018; Baumel et al., 2016). Gunther (2018) continues by explaining that caregivers and families are vital partners in providing care in the community. As part of the public, these caregivers need multiple skills and knowledge to ensure health promotion and prevention; this knowledge is needed to manage various life events by way of strengthening health literacy in households.

Communication technologies offer exceptional opportunities not provided by traditional healthcare, in that they can be tailored according to individual preferences, demographics, and health features. Such technologies are appropriate to enable the

user to use it anywhere they wish, at a time that suits them (Mitchell et al., 2014; Kreps & Neuhauser, 2010).

Emergent mHealth technologies supply support and information through their infrastructure and devices, and offers the potential for exponential growth in healthcare (Negash et al., 2018; Gururajan et al., 2008), mainly among caregivers in home and community care settings (Davis et al., 2016; Gentles et al., 2010). Caregivers of children with special needs could benefit from communication technology when their support needs are unmet (Mitchell et al., 2014; Park et al., 2016). Armoiry et al. (2018) reviewed literature and found that caregivers accept that communication technology provides the ability to communicate with healthcare professionals regarding caring for young people. Accordingly, *caregiving tasks* aided by the use of *mHealth technologies* could improve the health outcomes of the caregiver, as well as that of the care recipient (Chi & Demiris, 2015; Mitchell et al., 2014; National Alliance for Caregiving & AARP, 2009).

Some caregivers said that they try “to figure caregiving out” as they go along during their caregiving responsibilities (Cady & Belew, 2017); mHealth can connect caregivers to the information and knowledge they need to care for care recipients. Mobile technologies can create a gateway to information portals and knowledge, thereby enabling caregivers to guide their decision-making related to caregiving practices (World Bank, 2012; Kalil, 2009; Goel et al., 2013). Caregivers who are actively involved in accessing information portals improve their well-being (WHO, 2018a) and build their capacity (Mitchell & Kan, 2019) by this involvement.

Supporting caregivers could ensure effective caregiving, by supporting them with useful mHealth initiatives during challenging times. The effectiveness of technologies depends on the involvement of caregivers as end-users of the product. Each caregiver experiences unique challenges in various situations, which require customised support initiatives (Tang et al., 2018; Chi & Demiris, 2015). Chi and Demiris (2015) examined literature and found that caregivers’ outcomes improved significantly when they utilised communication technologies. These authors rank caregiver enhancements as follows: better emotional health, greater satisfaction with/confidence in technology use, greater skills/knowledge, improved quality of life,

increased support and coping skills, improved communication with healthcare professionals, greater cost-effectiveness, and better physical health. However, in contrast, Armoiry et al. (2018) found uncertain outcomes associated with caregivers using communication technology, although no studies indicated adverse effects. In most studies, the caregivers found the communication technology acceptable and apparently believed in its benefits.

### **3.3.3 Benefits and barriers of mHealth initiatives**

The field of mHealth is influencing healthcare delivery, and researchers are optimistic about this rapid innovation that is accepted by most caregivers. At the same time, one should acknowledge the *benefits and barriers* inherent in technology engagement by caregivers and community members.

Benefits and barriers of mHealth technology usage may comprise several factors, including socio-cultural elements, age, ethnicity, geographical area, demographic features, motivation, costs, literacy, culture, and applicability to the user. Acknowledging that these factors could hamper or enhance mHealth initiatives may influence the planning of the initiatives. Whether users (caregivers, in this case) adopt mHealth initiatives depends on their perception of its usability, including benefits and barriers of the mHealth initiative to them personally (Feroz et al., 2018; Miyamoto et al., 2016; Hardiker & Grant, 2011; Jimison et al., 2008).

#### **3.3.3.1 *Benefits of mHealth adoption***

Communicating mHealth as useful initiatives for caregivers will complement caregiving behaviour and meet healthcare needs. Research studies indicate that mHealth has several *benefits*, which are supported by anecdotal evidence in developing countries (Lee et al., 2018; Jusoh, 2017; Gautham et al., 2015; Burney et al., 2013) – **Table 3.1** lists the *benefits of mHealth adoption*.

**Table 3.1: Benefits of mHealth adoption**

Benefits	References
<b>To motivate caregivers to change their behaviour</b>	Alkiş and Findik-Coşkunça (2018); Kampmeijer et al. (2016); Hilty et al. (2015)
<b>To support caregivers (e.g., peer and social support; health support; electronic support; psychological support)</b>	Jusoh (2017); Njoroge et al. (2017); Berrouguet et al. (2016); Kampmeijer et al. (2016); Park et al. (2016); Li (2015); Dyer et al. (2012)
<b>To receive, exchange or access information</b>	Anderson-Lewis et al. (2018); Brinkel, Dako-Gyeke, et al. (2017); Jusoh (2017); Kampmeijer et al. (2016); Burney et al. (2013); Bhavnani et al. (2008)
<b>To educate caregivers</b>	Anderson-Lewis et al. (2018); Jabour et al. (2018); Bajwa (2014); Burney et al. (2013); Bhavnani et al. (2008)
<b>To save time (travelling)</b>	Brinkel, Dako-Gyeke, et al. (2017); Jusoh (2017); Brinkel et al. (2014); Malvey and Slovensky (2014)
<b>Reliable and easy to use</b>	Brinkel, Dako-Gyeke, et al. (2017); Kampmeijer et al. (2016); Delponte et al. (2015); Jimison et al. (2008)
<b>Accessible and available</b>	Ploeg et al. (2017); Becker (2016); Davis et al. (2016); Kampmeijer et al. (2016); Malvey and Slovensky (2014)
<b>Convenient</b>	Malvey and Slovensky (2014); Oksman (2010); Jimison et al. (2008)
<b>Helps at home</b>	Kampmeijer et al. (2016); European Commission (2014); Malvey and Slovensky (2014)
<b>Cost-effective</b>	Brinkel, Dako-Gyeke, et al. (2017); Ploeg et al. (2017); Malvey and Slovensky (2014); Bishwajit and Dawah (2014); Burney et al. (2013)
<b>Equal healthcare</b>	Bishwajit and Dawah (2014); Malvey and Slovensky (2014); Akter et al. (2010)
<b>Community development and capacity building</b>	Feroz et al. (2018); Brinkel, May, et al. (2017); Malvey and Slovensky (2014)
<b>Quality healthcare services</b>	Malvey and Slovensky (2014); Burney et al. (2013)

### 3.3.3.2 Barriers to mHealth adoption

Although mHealth holds definite benefits to caregivers and healthcare, one should also be aware of the *barriers* when planning mHealth initiatives – **Table 3.2 lists barriers to mHealth adoption.**

**Table 3.2: Barriers to mHealth adoption**

Barriers	References
<b>Inadequate funding</b>	Scott and Mars (2013, 2015)
<b>Inadequate policies and legislation</b>	Kampmeijer et al. (2016); Townsend (2015); Mars and Scott (2010)
<b>Lack of government and political awareness</b>	Townsend (2015); Jahan and Chowdhury (2014); Ivatury et al. (2009)
<b>Cultural challenges</b>	Scott and Mars (2015); Townsend (2015)
<b>Inadequate resources (human, technical and infrastructure)</b>	Kampmeijer et al. (2016); Scott and Mars (2015); Jahan and Chowdhury (2014)
<b>Illiteracy</b>	Jusoh (2017); Malvey and Slovensky (2014); Chigona et al. (2011)
<b>Poor digital literacy</b>	Jusoh (2017); Scott and Mars (2015); Jahan and Chowdhury (2014)
<b>Resistance to change</b>	Scott and Mars (2013, 2015)
<b>High costs</b>	Jusoh (2017); Jahan and Chowdhury (2014); Scott and Mars (2013); Akter et al. (2010)
<b>Poor information and education culture</b>	Scott and Mars (2015); Jahan and Chowdhury (2014)
<b>Limited technology access and training</b>	Kampmeijer et al. (2016); Jahan and Chowdhury (2014); Malvey and Slovensky (2014); Chigona et al. (2011); Akter and Ray (2010)
<b>Socio-demographic challenges (age, gender, income levels)</b>	Eren and Gökalp (2018); Kampmeijer et al. (2016); Khatun et al. (2016); Khatun et al. (2015)
<b>Poor quality of information on the Internet</b>	Park et al. (2016); Knapp et al. (2011)
<b>Not consumer-centred</b>	Park et al. (2016); Schnall et al. (2016); Orlowski et al. (2015)

Barriers	References
Language barriers	Feroz et al. (2018); Hartzler and Wetter (2014)

The benefits and barriers listed in Tables 3.1 and 3.2 intend to provide an overview of the possibilities when caregivers adopt mHealth. If the benefits fuel adoption, mHealth could shape the mental healthcare of adolescents by transforming the caregiver domain.

### 3.4 CAREGIVERS' READINESS TO ADOPT MHEALTH INITIATIVES

Knowing more about the benefits and barriers of mHealth adoption leads to the question, how do benefits and barriers of mHealth adoption impact the readiness and adoption of mHealth initiatives by caregivers?

Khatun et al. (2016; 2015) developed a conceptual model to determine an underserved community's *readiness* for mHealth *adoption*, and they state that it is important that the community is ready for its implementation, prior to intervention design. These authors described three domains influencing mHealth readiness, namely, technological, motivational, and human resource readiness. Insight into these three domains could guide researchers during the development process of mHealth initiatives. The abovementioned domains highlight some of the benefits listed in Table 3.1. Technological readiness includes concepts such as accessibility, availability, affordability, and technological literacy of users. Motivational *readiness*, furthermore, comprises users' intentions, attitudes, and trust to use mHealth initiatives. The last domain portrays the human resource readiness of users, that is, socio-demographic elements, possession of mobile phones, and mHealth services awareness. These domains imply that mHealth benefits can potentially predict the caregivers' *readiness* to accept an mHealth initiative, especially in resource-constrained settings.

Hardiker and Grant (2011), Jennett and Gagnon (2005), and Feroz et al. (2018) express similar views about mHealth readiness. All three sources characterise certain determinants of users' uptake of mHealth initiatives. Some factors that

illustrate *readiness* are demographic features, affordability of mHealth, users' digital literacy and capabilities, trust in mHealth technology, socio-cultural factors, and geographical area. One further perspective mentioned by Hafeez-Baig and Gururajan (2010) is that mHealth *adoption* hinges on its benefits and barriers. From the researcher's viewpoint, these determinants of mHealth adoption envision various possibilities for formulating a purposeful framework for the development of mHealth initiatives for the South African caregiver.

Ellery and Ellery (2012) point out, furthermore, that researchers should present mHealth technology in "a meaningful, manageable, and comprehensible manner" to ensure better user *adoption*, while Burney et al. (2013) state that mHealth technologies should be made more available to the beneficiaries. Linking to this idea further, is designing an mHealth initiative according to user preferences, thereby ensuring successful adoption (Ellery & Ellery, 2012). Neither acceptance nor adoption guarantee implementation of mHealth. Successful implementation of an initiative does not occur in isolation, but through collaboration with influential stakeholders from provincial and national departments of health, together with well-defined regulatory legislation in the relevant sectors.

Feroz et al. (2018) and Aamir et al. (2018) report another challenge regarding mHealth adoption. Both discuss the limited engagement of government and the public in mHealth adoption, including insufficient mHealth policies in LMICs. Governments should, as a priority, set policy guidelines, as a crucial determinant of mHealth readiness that will ensure effective mHealth services (Khatun et al., 2015; WHO, 2011). Lack of policy guidelines and strategic planning by a government could influence widespread mHealth adoption. Jahan and Chowdhury (2014) assert that mHealth services should be regulated by national information infrastructure, and supported and connected by global information infrastructure. In the next two sections, the researcher will briefly discuss international and national regulation regarding mHealth.

### 3.4.1 International regulation

mHealth, as a subset of eHealth, needs similar regulation and policies as eHealth, and should involve multiple sectors. Governments should collaborate with the healthcare and mobile communications sectors to support mHealth initiatives by providing regulatory guidelines (Townsend, 2015; WHO, 2011). Transformational leadership in governments is pivotal to ensure *policymaking and regulations* supporting mHealth development and implementation (Townsend, 2015; World Bank, 2012; WHO, 2008b). Most governments in LMICs lack interest in adopting mHealth and ICT technologies.

Legislation in some developing countries is also lagging, while more individuals are ready to adopt this innovative solution as a supportive health initiative in resource-constrained environments. Even though governments in developing countries have access to plenty of reports, analysis, and guidance from the international arena, they believe that such information does not always apply to their context (Peters, 2008). Consequently, they neglect making regulatory and legislative provisions to regulate the use of mHealth in healthcare. mHealth *legislation* can “disappear” between various policies formulated for eHealth, the health sector, ICT, government policies, and human rights issues. Limited investment and funding shortages also discourage developments in the mHealth landscape (Feroz et al., 2018; Townsend, 2015; Scott & Mars, 2013).

The question that arises, then, is why governments of developing countries do not actively create, plan and formulate context-applicable *legislation* that fits their situations. Furthermore, in addition to questions about formulating plans, we could ask why governments do not implement legislation and policy frameworks that will ensure safe, secure, and trusted digital participation by public individuals (Gillwald, 2018; Gillwald et al., 2018; Mechael et al., 2010). Ignorance of the capabilities of and political barriers facing adoption of mHealth by policymakers were mentioned in literature as some of the barriers to legislation formulation (Peiris et al., 2020; Townsend, 2015; Jahan & Chowdhury, 2014).

The WHO (2008b) encourages eHealth (including mHealth) strategies and policy development, to ensure sound standards of ICT guidelines in healthcare. Good

governance can facilitate legislation, investments, and infrastructure when planning ICT frameworks for diverse, multi-language communities in a digital world.

Sustainable strategies and effective governance of mHealth initiatives can be established through multiple partnerships between the government, local officials, healthcare organisations, universities, the private sector, and sponsors (Barkman & Weinehall, 2017; WHO, 2012b; World Bank, 2012; WHO, 2011). Further infrastructure challenges facing mHealth diffusion in some countries are problems relating to inadequate funding, legal and regulatory issues, lack of political will and interest, technical problems, and competing interests. Various political, social, economic, and technical environments can influence mHealth adoption and relevant legislation (Malvey & Slovensky, 2017).

A survey to determine the existence of national policies among the WHO member states shows that 58% of these countries had eHealth strategies in place, and 57% of the member states mentioned telehealth policy, specifically, within their national eHealth policy, or reference to it. Some member states (19%) indicated they had social media policy within government organisations, while 33% of member states reported policies regarding medical liability, and 47% of member states had policies about safety, quality, and standards of health-related information (WHO, 2016b).

Hämäläinen et al. (2008) summarised the general aims of European member states' eHealth policies, namely, public-oriented healthcare, quality care, improving communication between parties concerned, efficiency, and healthcare access. Thus, supporting mHealth environments is the government's responsibility. This means that individuals (caregivers) and healthcare professionals have the right to vital, available, actionable information that could protect their own health, as well as that of the care recipients (Royston et al., 2015; Bhaumik et al., 2013).

An mHealth policy in the healthcare context can prescribe standard principles on how the mHealth strategy should be planned, implemented, sustained, and evaluated by all relevant stakeholders. This is currently a challenge in South Africa.

### 3.4.2 South African legal framework and regulation

It is a given that national governments and policymakers have to work together to guarantee scaling up of mHealth initiatives in healthcare; however, how is this cooperation impacted by incomprehension or weak political will? The South African mHealth strategic plan of 2015-2019 (Department of Health, RSA, 2019), refers to the absence of mHealth and eHealth framework to guide mHealth projects. This strategic plan continues by saying that a standardised framework is necessary to guide policymakers and healthcare managers during mHealth planning and implementation. Governance and *regulation* are seen as the fourth priority, according to this plan. A key action was to develop a national mHealth policy framework, which was finalised and adopted by the National Health Council (Department of Health, RSA, 2019).

mHealth policy frameworks are particularly important to healthcare professionals, healthcare organisations, PHC clinics, hospitals, service providers, mobile network operators, and mHealth providers. Such a policy can set certain protective conditions regarding privacy, data protection, cybersecurity, information access and trusted environments (Gillwald et al., 2018; MEASURE Evaluation SIFSA, 2016). *Legislation and regulatory* organisations should protect users by providing regulation in the mHealth setting; however, there seems to be ambiguity regarding mHealth regulation in *South Africa*. Regulations struggle to keep up with rapid technological advances, though regulatory bodies must monitor the situation. See **Table 3.3** for the current legislation applicable to mHealth and caregivers in South Africa.

**Table 3.3: Current South African legislation (acts, policies, frameworks, committees and associations) applicable to mHealth and caregivers**

Forms of legislation	Function/description
<p><b>Protection of Personal Information (POPI) Act of 2013</b> South Africa (2013)</p>	<p>The act specifies minimum requirements for the processing of personal information, which is defined as information on any identifiable living person (or, in South African terms, any juristic person, which includes companies).</p>
<p><b>The Independent Communications Authority of South Africa Act No. 13 of 2000 (ICASA Act)</b> South Africa (2000)</p>	<p>Established a regulator to oversee broadcasting, telecommunications, and postal services. ICASA licenses broadcasters, signal distributors, and providers of telecommunication services – including mobile network operators – and issues the frequency spectrum on which they operate.</p>
<p><b>Electronic Communications Act of 2005</b> <b>Electronic Transactions Act of 2005, and the Broadband Policy</b> South Africa, (2006b)</p>	<p>These acts aim to address issues of accessibility, availability, and affordability of ICT services in the country.</p>
<p><b>Nursing Act, 2005 (Act No. 33 of 2005)</b> South Africa (2005)</p>	<p>“To uphold and maintain professional and ethical standards within nursing by controlling and exercising authority over practices pursued by registered nurses, midwives, enrolled nurses, and enrolled nursing auxiliaries. Because nurses are the biggest workforce sector in public health facilities, the SANC [South Africa Nursing Council] should also guide how nurses should engage with mHealth initiatives.”</p>
<p><b>Health Professions Act, 1974 (Act No. 56 of 1974)</b> South Africa (1974)</p>	<p>To serve and protect the public and to provide guidance to registered healthcare practitioners.</p>
<p><b>Children’s Act 38 of 2005</b> South Africa (2006a)</p>	<p>“A comprehensive national strategy aimed at securing the provision of prevention and early intervention programs to families, parents, caregivers, and children across the Republic.”</p>
<p><b>District Health Management Information Systems (DHMIS) Policy</b> South Africa (2011)</p>	<p>It provides a formal regulatory framework for the DHMIS under the National Health Act of 2003, which empowers the minister to establish the legal framework for health information systems.</p>
<p><b>The National Cybersecurity Policy Framework (State</b></p>	<p>To promote and ensure a comprehensive legal framework governing the cyberspace, and aims to</p>

Forms of legislation	Function/description
<b>Security Agency, 2015)</b> South Africa (2015)	implement an all-encompassing approach on all the role players
<b>The National Health Normative Standards Framework for Interoperability in eHealth (HNSF) (Department of Health, 2014)</b> CSIR and Department of Health (2014)	The HNSF sets the framework for interoperability of eHealth, and specify a standards-based health information exchange and an enterprise architecture as central to the implementation of interoperability going forward for the healthcare in the public sector.
<b>National Health Information Systems Committee of South Africa (NHISSA)</b> Health Information Task Team (2011)	Includes the “development of policies and regulations to govern information management in the health sector”.
<b>White Paper on Families in South Africa</b> Department of Social Development, RSA (2013)	Views the family as a key development imperative and seeks to mainstream family issues into government-wide policy-making initiatives in order to foster positive family well-being and overall socio-economic development in the country.

Governments are responsible for providing enabling environments for mHealth adoption within its legal jurisdiction, and South Africa’s political and legislative nature should be considered. However, national, provincial, or local administrations may function according to the leading political party within that jurisdiction, and this could result in poor governance, human resource scarcity, absent leadership, inadequate infrastructure, and lack of interoperability between all stakeholders (Kotzé & Alberts, 2017; Department Telecommunications & Postal Services, RSA, 2016; CSIR and Department of Health, 2014). Effective scaling up of mHealth adoption in *South Africa*, aimed at the general public, is fundamental to ensuring service delivery in the health sector of developing countries, and to address healthcare needs (Kotzé & Alberts, 2017; Botha & Booi, 2016; Iyawa et al., 2016).

Jahan and Chowdhury (2014) propose specific conditional policy initiatives for developing countries, to enhance mHealth implementation effectively. Such policy initiatives include capacity building of facilities by governments and healthcare

professionals to promote mHealth, to construct mobile networks, especially in remote areas, to provide financial and government support and ensure a “reliable nationwide mobile communication system”, which is, according to the authors relevant to any individual. Policies to anchor mHealth technology adoption by individuals, and strengthening health services should be priorities for policymakers and governments. Research is necessary in this area, to identify gaps to inform policymakers, health services, and the government. Governments have even more responsibility to empower underserved communities with timely health information and education, knowledge, and skills. MHealth technologies that are monitored by structured legislation could provide such services (Anderson-Lewis et al., 2018; Botha & Booie, 2016; Mars & Scott, 2010; Bhavnani et al., 2008). LMICs in the sub-Saharan African region (South Africa included) can benefit from using mobile technology in healthcare delivery (Sezgin, 2018; Royston et al., 2015) to empower caregivers in their caregiving activities. Some authority should regulate delivering information to families and caregivers through mHealth initiatives.

The Children’s Act No. 38 of 2005 (South Africa, 2006a), in Section 144, sets certain principles related to caregivers and families caring for children. These principles have significant consequences in the broader domain of mHealth information and caregivers. The principles indicate the necessity of interventions for caregivers and families, to empower them, and to provide access to information and services. Furthermore, such interventions should focus on caregiver participation and involvement. Section 145 continues with a statement from the minister, who states that there should be “*a comprehensive national strategy aimed at securing the provision of prevention and early intervention*” programmes to families, parents, caregivers, and children across the Republic of South Africa.

What these sections of the Children’s Act are trying to do, then, is to lead policymakers and relevant stakeholders regarding the constitutional right of caregivers (and families) to be supported by the government of *South Africa*. By focusing on caregiver support, the deeper problem of government underperformance regarding its constitutional responsibility to scale up caregiver support networks and services could be overlooked (Mkhwanazi et al., 2018). Governments should

capitalise on supporting initiatives for caregivers, because they play a vital role in influencing the well-being of children.

Unsatisfactory performance by the government in coordinating and implementing policies may be due to fragmented administration and poor leadership. Capricious government assurances about delivering *policies* cloud policy formulation and, eventually, policy implementation. Despite much criticism and execution challenges of South Africa's Policy Framework for Families, the country remains one of a few that achieved the adoption of such a policy (Department of Social Development, RSA, 2013), and the Department of Social Development approved the White Paper on Families in October 2014 (Rabe, 2017). The White Paper on Families aims to strengthen and empower families, promote family life through optimal opportunities, build family capacity, create a sense of community, and promote social interaction. Meaningful difficulties related to implementation were experienced, causing the White Paper on Families to "exist on paper but not in practice" (L. Patel et al., 2018). In addition to these aims, the White Paper on Families underscores three priority strategies, that is, 1) the promotion of healthy family life; (2) strengthening families (including providing health and community support); and (3) preserving families (through prevention and early interventions) (L. Patel et al., 2018; Rabe, 2017; Department of Social Development, RSA, 2013). Certain challenges related to the execution of The White Paper on Families were identified in a review by L. Patel et al. (2018), namely, lack of knowledge, poor policy integration between government and non-government sectors, "inadequate performance monitoring and evaluation of staff and programs", lack of clear guidance on implementation and outcome assessment, indistinct policy budget provisions, and limited direction through local and provincial family forums.

The White Paper on Families matters, because families are responsible for personal caregiving, including essential behaviour towards the care recipient. The researcher wants to highlight the relevance of one objective set by the White Paper on Families, which is to promote socialising, nurturing, caring, and supporting of the skills of caregivers through capacity building. These skills are vital to meet family and caregiver demands (Department of Social Development, RSA, 2017).

Ultimately, when it comes to capacity building, more work is necessary to ensure that caregivers receive adequate information to fulfil their caregiving roles. Information and education strategies for families, in view of L. Patel et al. (2018), are an essential task to be enforced by the Department of Social Development through the implementation of the White Paper on Families. This view matches that of Richter et al. (2018) and the White Paper (Department of Social Development, RSA, 2013), namely, that the government's responsibility is advocacy for families' need for healthcare information and education.

Returning briefly to the policy vacuum regarding mHealth, the researcher believes that the South African government should commit to policy-focused caregiver *legislation*, starting with mHealth and the White Paper on Families policies. It is time to take action on the dissemination of healthcare information and education to caregivers through practical initiatives. MHealth initiatives have proven to be practical and promising regarding supporting caregivers globally (Corralejo & Domenech Rodríguez, 2018; White et al., 2017; Royston et al., 2015; Uys, 2015). There is clear proof that the deployment of mHealth initiatives may be meaningful, though not without stakeholder involvement.

Altogether, mHealth technologies, with effective legislative frameworks and government support, might offer a solution to unmet healthcare needs among the underserved population. Such technologies are available in various platforms that suit individual preferences and economic situations.

### **3.5 MOBILE PHONE TECHNOLOGY**

Mobile phone technologies that are used for mHealth enable individuals to engage with several services with minimal effort, due to their accessibility, availability, and independent location abilities (Sezgin, 2018; Istepanian et al., 2003). Mobile phone technology includes wireless technology, such as mobile phones, smartphones, and tablets, which are integral parts of most people's lives – they already embrace technology (Botha & Booie, 2016; Corydon et al., 2016). Developing countries, surprisingly, surpassed developed countries regarding penetration of mobile technology. This growth in mobile technology ownership, as well as mobile

subscriptions, may be the answer to the burdened healthcare system. Cost-effective healthcare services can be provided through wireless communication technologies, which demonstrate tremendous capability to reduce health disparities (Anderson-Lewis et al., 2018; Istepanian & Woodward, 2017; Burney et al., 2013; Danis et al., 2010).

Mobile technology is not only about connecting to other people, but can be utilised effectively in healthcare, due to diverse functionalities, such as short messaging services (SMS), social media, applications, and access to the Internet/Web (Anderson-Lewis et al., 2018; Botha & Booie, 2016; Klasnja & Pratt, 2012). Traditional face-to-face healthcare visits are challenged by limited resources (human, physical, and financial) and may be substituted by mobile phones as “healthcare in a pocket” when demanded (Klasnja & Pratt, 2012; Danis et al., 2010). The researcher has personally experienced overburdened healthcare services characterised by challenges, such as high numbers of care recipients who have to be seen by healthcare professionals, one recipient at a time. These face-to-face visits traditionally occur despite staff shortages in most healthcare facilities in South Africa. In-person healthcare visits can be limited by the implementation of *mobile technology* support to the broader population simultaneously, independent of individuals’ whereabouts or situations.

A mobile phone is “in our hand, in our pocket or purse”, and serves as a personal companion. The convenience of mobile phones may translate into increased opportunities for healthcare services, anywhere, at any time, to anyone (Istepanian & Woodward, 2017; Goel et al., 2013; Klasnja & Pratt, 2012).

### **3.5.1 The mobile phone as the caregiver’s vehicle to support**

Mobile phones have specific functionalities that are useful for users in different ways. Exploring this innovative avenue as a vehicle in healthcare delivery may be worthwhile for the caregiver. Mobile phone users commonly use their devices to send and receive text messages, pictures, and videos (Pew Research Centre, 2018; 2015). Such functions can also be valuable in the healthcare context, as mentioned before, and the researcher strongly believes in the possibilities of these functions.

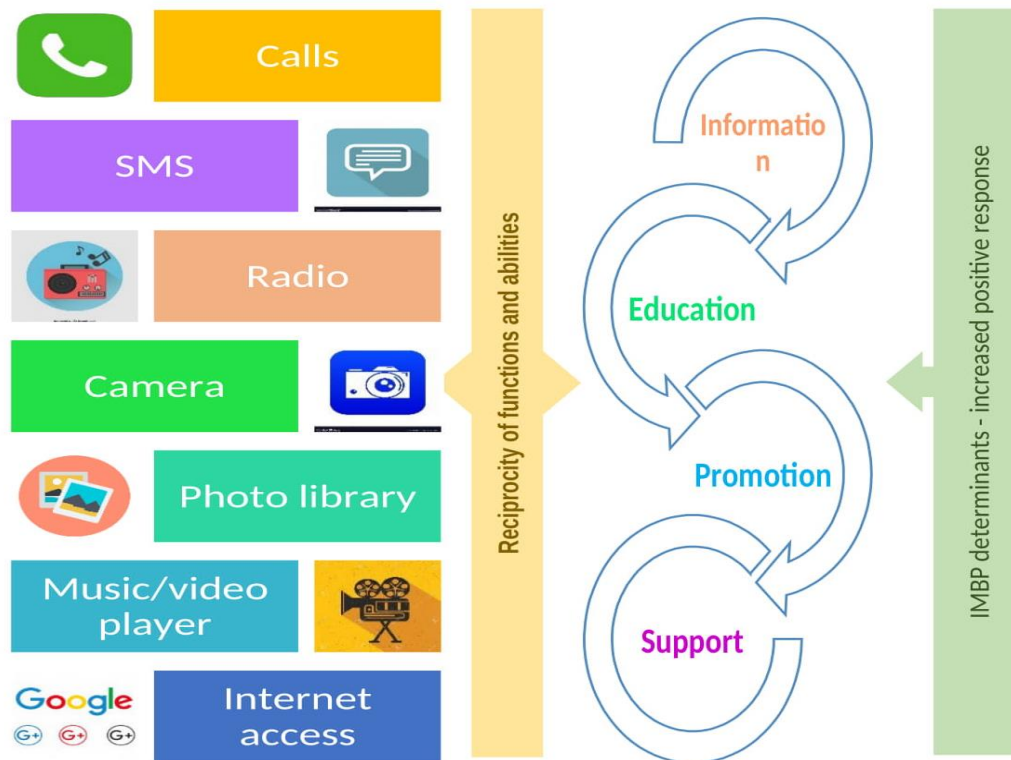
Research studies demonstrate how mobile phones are smart inventions for communicating information to individuals in the community while supporting healthcare services (Malvey & Slovensky, 2017; Baig et al., 2015; Malvey & Slovensky, 2014; Goel et al., 2013; Sloninsky, 2008; Kaplan, 2006). Four essential features of using mobile phones as healthcare support initiatives are 1) acceptance of the mobile phone because of its technical abilities, 2) the phone is carried around by the person, 3) the person is attached to their mobile phone, and 4) contextual characteristics (Pew Research Centre, 2018; 2015; Klasnja & Pratt, 2012). Mobile phones play such an important role in peoples' lives that, if there is no electricity, people will walk long distances just to charge their phones, or will pay others to charge their phones (Woodard et al., 2014).

Some customised functionalities of mobile phones include reminders, calendar prompts, personal settings, and message preferences. Adoption and acceptance of mobile phones could be increased by making these personal choices available to each caregiver (Proudfoot, 2013; Klasnja & Pratt, 2012). Such appealing features of mobile phones could possibly contribute to effective healthcare communication, education, support, and information (Goel et al., 2013), and have a positive impact on caregivers' lives (Frisbee, 2014; Talley et al., 2014; Akter & Ray, 2010; Reese et al., 2012). Features of mobile phones, referred to as delivery modes by Lee et al. (2018) and technical capabilities by Patrick et al. (2008), portray the following functionalities: SMS, phone calls, voice and video calling, recordings, Internet access, email, social networking, multimedia services (MMS), e.g., photos and videos, notetaking, software applications, camera and radio (Lee et al., 2018; Aryee, 2014; Ventola, 2014; Free et al., 2013; Akter & Ray, 2010; Patrick et al., 2008). Informational images or videos can be transferred through the SMS and MMS functions, while voice and video calling creates communication between two or more parties. Furthermore, information can be accessed through Internet browsing, and from social network platforms. Additional features include data storage capabilities, and storing information images or video files that can be viewed later at a convenient time (Ventola, 2014; Lefebvre, 2009; Patrick et al., 2008).

It has become commonplace to distinguish between basic and smart *mobile phones*. Basic mobile phones have features such as making and receiving phone calls and

sending and receiving SMSs, but have limited computing power, while smartphones are more advanced, almost like mini computers (Keisling, 2015; Klasnja & Pratt, 2012; World Bank, 2012). Given the features of mobile phones, one can deduce that the mentioned functionalities could offer a range of opportunities to provide caregivers with support through acquiring, retrieving, and sharing health information.

The researcher attempted to visualise the relationship between *mobile phone* functionalities, opportunities, and intention of behaviour, according to the IMBP model (Fishbein & Yzer, 2003). Determinants influencing the caregivers' intention to participate in behaviour are attitude, norms and self-efficacy, while skills and environmental constraints impact actual performance of behaviour (see **Figure 3.1**). SMS, MMS, and phone calls give the individual (caregiver) the opportunity to either call, send or retrieve information from another individual (peer or professional), a group (support), or the Internet. Through this process, the caregiver receives health information, health promotion, and can be educated regarding a healthcare topic. The essence of this argument is that, when caregivers use any of the mobile phone functions to get information, health promotion, education, and support, they would probably acquire some skills and abilities, and improve their caregiving behaviour. In making this comment, the researcher anticipates reciprocal outcomes, in that caregivers will also share information learned through mobile technology abilities, and adapt caregiving behaviour.



**Figure 3.1: Mobile phone functions, opportunities, and caregiving behaviour**

Sloninsky (2008) and Hall et al. (2014) illustrate the topic of opportunities further by reporting on the interactive abilities of mobile phones, for instance, calling a healthcare professional or another caregiver needing support or advice, or inquiring about assistance by sending an SMS and receiving a response through either an SMS or MMS (Bakker et al., 2016). This may sometimes involve an effortless action when the end-user receives motivational images or healthcare messages (Mwantimwa, 2019; Klasnja & Pratt, 2012) and does not physically have to visit a clinic. Understanding the value of mobile phone opportunities in healthcare adds weight to the argument that caregivers will benefit from mHealth technology, even if they only have basic mobile phones, that can only send and receive instant informational messages. A brief discussion on messaging services, call services, and mobile applications will follow.

### 3.5.2 Messaging services

One of the mobile phone functions widely used for mHealth is transferring and exchanging messages through either text or multimedia. SMS, popularly referred to as texting or text messages, involves sending a text-only message to an individual or multiple people, whereas MMS incorporates multimedia, such as text messages, pictures, video clips and audio to individuals or groups. SMS offers instant messages that are asynchronous and inexpensive. Asynchronously messages are read or replied to at a convenient time. MMS can be a little pricier, because of data costs and usage of multimedia content (Eren & Gökalp, 2018; Abrams et al., 2012; Norris et al., 2013; Fjeldsoe et al., 2012; Vodopivec-Jamsek et al., 2012; Le Bodic, 2005). Both *messaging services* present opportunities for healthcare education dissemination to the population, or mass distribution of healthcare information in an under-resourced healthcare system (Norris et al., 2013; Abrams et al., 2012). Even for caregivers in South Africa, it is relatively uncomplicated to send and receive messages (SMS or MMS), irrespective of the geographical location and literacy level of the end-user.

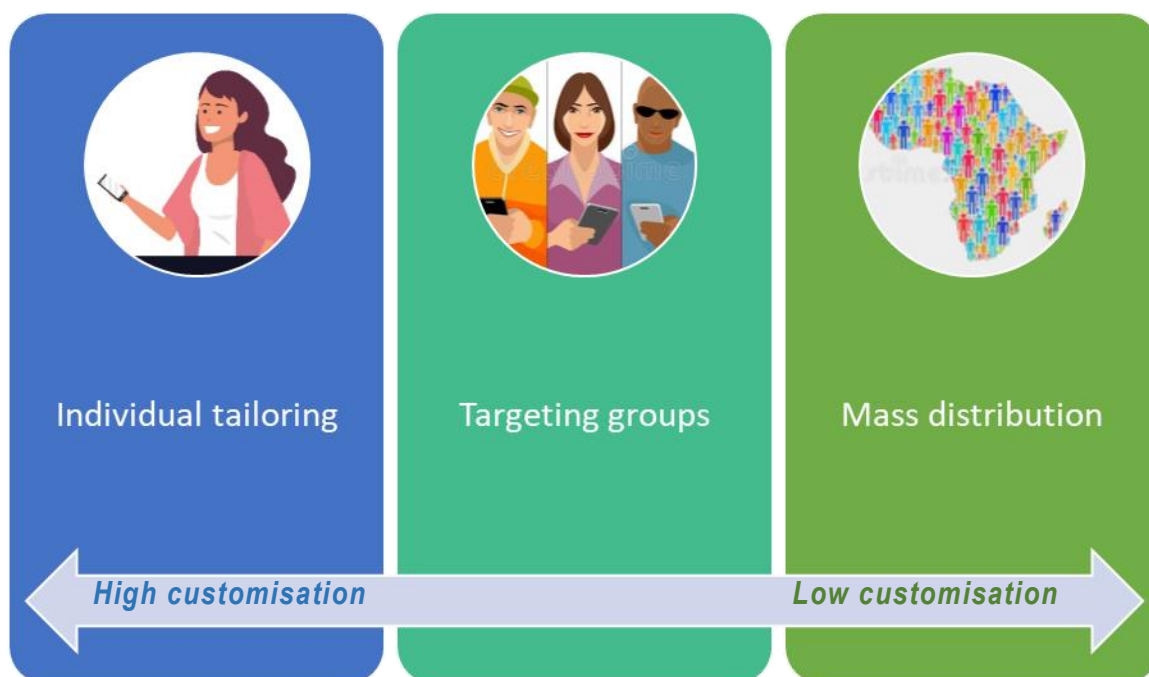
*Text and video messages* require that the user stands or sits still to view the message, while audio messages, comparatively, are more convenient, as the user may move around while listening to the message. Shorter videos are less time-consuming, while text messages are more convenient to access during network shortages. Audio messages do not excite individuals, though it is easier to use (Oksman, 2010). Time-consuming actions may predict caregivers' willingness to use and adopt certain functionalities of mobile phones.

Vashistha et al. (2016) and Abdel-Wahab and El-Masry (2010) suggest another viewpoint regarding the contextual relevance of using MMS to share information through storytelling and folk media. Video messages and calls could, furthermore, demonstrate specific behaviour or disseminate information through sight and sound and that is more interesting to the end-user (Buhi et al., 2013; Oksman, 2010) than just a text message. These video formats have the potential to enhance healthcare in resource-constrained communities by sending informational "stories" that are contextually appropriate (Vashistha et al., 2016; Chidubem, 2012). Vashista et al.

(2016) argue that *multimedia storytelling* would be even more meaningful if community members were part of the video creation. Storytelling has been part of people's lives since the beginning of time. The format of stories varies from traditional oral storytelling, to recently, printed media, and, currently, digital formats. People are social beings, and they communicate through stories and using words (Finger et al., 2008). Text, video, and audio could be valuable vehicles for delivering stories in the digital era.

Text messages are popular due to the following characteristics: they can reach the broader public, "low cost and recipient burden", individual behaviour change can occur at any place and at any time, customisation is possible, and virtual connection allows interaction. Disadvantaged and illiterate individuals accept this way of communication (Buhi et al., 2013; Fjeldsoe et al., 2012; Vital Wave Consulting, 2009). Other attributes of SMS mentioned by Le Bodic (2005) are that customised messages can be sent to multiple recipients simultaneously and in the language of their choice. By identifying these SMS characteristics, it is possible to highlight these attributes as essential in the adoption and utilisation of such initiatives in healthcare in resource-constrained environments. An informational message that is meaningful and tailored according to caregivers' needs, in a language that they will understand, may have the potential to address healthcare access challenges faced by caregivers.

The preceding discussion drew our attention to the work of Kreuter and Wray (2003) and Hawkins et al. (2008), who defined the concepts of *tailored*, *targeted*, and *mass health communication*. They refer to tailoring as communicating specific health messages to an individual, while targeted communication embodies group communication based on shared similarities. Mass communication focuses on sending bulk messages to a heterogeneous population. Individual appropriation and creation of relevant communication material according to culture, personal preference, and suiting the individual define tailoring. Tailoring proves to be more difficult during mass health communication than in individual customisation. **Figure 3.2** presents an adaptation of Hawkins' visualisation of tailoring, targeted, and mass health communication.



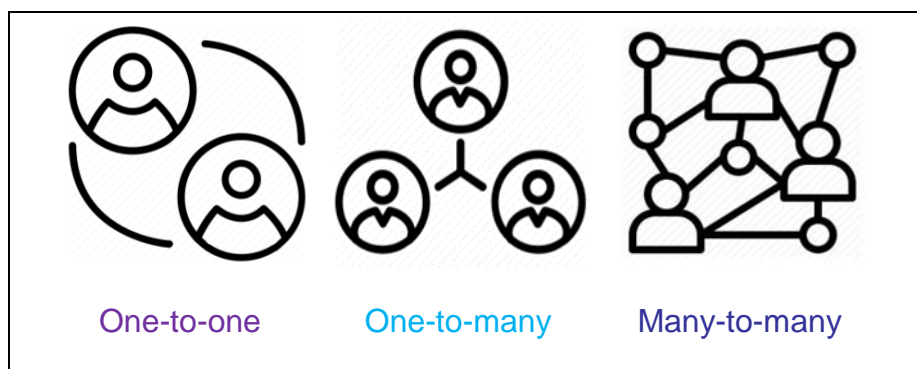
**Figure 3.2: Tailoring, targeted and mass health communication**

Source: Adapted from Hawkins (2008)

According to Kreuter et al. (1999), the “one size fits all approach of mass health communication may influence health-related decisions and behaviours”, because of the bulk production of general messages, and because it does not focus on individual situations. Rimer and Kreuter (2006) determined that health communication, *tailored* to individuals, culture, and beliefs, may be more worthwhile to the end-user than generic messages. This implies that *tailored* health messages that address individual preferences and which keep the target population (caregivers) in mind, could potentially influence their behaviour positively. Head et al. (2013) report significant results from a combination of tailored and *targeted* interventions. They also found that constant, fixed messages were less effective than individual messages focused on specific population characteristics, and sent occasionally.

More individualised messages take precedence over tailored messages, according to Orr and King (2015), and both these approaches are more effective than sending general messages. Furthermore, they predict that two-way communication would be more beneficial than one-way communication. Messaging offers either one-way or two-way, as well as horizontal and vertical flow of communication. One-way

communication does not allow human interaction, whereas two-way communication creates interaction between the sender and receiver (Eliasson & Olsson, 2018; Källander et al., 2013; Dèglise et al., 2012; Källander, 2010). “*Multiway communication can vary the number of senders and receivers, including 1-to-many, many-to-1, and many-to-many communication*” (Källander et al., 2013). **Figure 3.3** explains various types of communication formats, as interpreted visually by the researcher. Vertical flow of communication occurs when there is a top-down approach with little participation from the receiver, while horizontal communication allows feedback and responses between parties (Chapman & Slaymaker, 2002). Two-way communication exchanges knowledge, information, or support (Savolainen, 2017) and could occur between individuals or healthcare providers, between healthcare providers and public citizens, or between peer supporters (Vodopivec-Jamsek et al., 2012). Such participatory interaction is meant to, remotely, give either advice or health information, or to remind end-users about behavioural practices (Becerra-Fernandez & Sabherwal, 2008). SMS or MMS allows either one-way or two-way communication.



**Figure 3.3: Communication formats**

*Messaging* is an effective means of sending messages to and receiving messages from large numbers of users, either unidirectionally or bidirectionally. Some other features worth mentioning are that users can choose the message format, and can send and receive messages according to their phone type, they can ask questions, messages can be delivered, even if phones are switched off or have a flat battery, and do not need fast Internet connections or daily electricity (Ames et al., 2019;

Berrouiguet et al., 2016; Dèglise et al., 2012). Understanding these features is important and needs to be considered when planning mHealth initiatives for caregivers as the target population, especially in resource-constrained environments.

Several studies have investigated the *feasibility* of SMS or MMS interventions.

- For instance, Zurovac et al. (2013) found that caregivers in Kenya, where 30% of the population lives below the poverty line, selected to use text messaging (SMS).
- In another study, by Chu et al. (2019), parents of adolescents received daily text messages (SMS) to promote their competence and mental health literacy. They reported improved levels of parents' competence, knowledge to seek help, and parent/adolescent communication, with lower stress levels.

Three other studies focused more on maternal care.

- Firstly, two tailored voice messages (MMS) were delivered weekly to low-income expectant or new mothers in Bangladesh. This intervention resulted in increased knowledge and positive behaviour by these participants (Chowdhury et al., 2019).
- Secondly, pregnant women in slum areas in Mumbai received tailored educational voice messages twice weekly in the participants' preferred language. Their outcomes proved to be increased knowledge regarding parental practices (Murthy et al., 2019).
- In the third study, respondents in rural Malawi (including pregnant or childbearing women and caregivers of young children) could call a toll-free hotline to receive information, advice, tips, and reminders via voice or SMS messages weekly. They concluded that SMS is the preferred method to deliver health information, and respondents were satisfied with the intervention. Furthermore, respondents changed or intended to change behaviour after they received messages and reported that they had acquired new information (Crawford et al., 2014).

Although the abovementioned studies used different target populations, it still sheds light on the value of SMS and MMS for populations who share similar demographic profiles with the current study population.

This discussion adds weight to the attractiveness of messaging as a promising avenue for healthcare delivery. Recognising this attraction may lead the way in delivering healthcare to caregivers through personal communication. This personal connection allows human interaction on some level, either through receiving a written message, listening to a voice message, or calling someone (Hall & Bierman, 2015; Kim & Lee, 2014; Klasnja & Pratt, 2012).

### **3.5.3 Call services**

Being wireless, mobile phones, differ from fixed landline telephones, in that mobile phones can send and receive calls independent of the individual's location. Synchronous communication commonly occurs when two individuals converse simultaneously during the bi-directional call process. A caller can quickly connect to another individual, even in developing countries, where there is high mobile phone penetration (As-Saber & Hossain, 2019; Scolari et al., 2012; Coiera, 2003; Le Bodic, 2005)

Two types of voice *call services* are available. *Firstly, there* is the typical call between two mobile phone users, as well as the conference call, between three or more people. *Secondly, there* is interactive voice response (IVR), which is an automated, computer-based service (with or without toll-free numbers). An automated call system does not involve human input, but can connect a caller to either a human or machine operator, or can play some information (Posadzki et al., 2016; Woodard et al., 2014). An *IVR system* supplies automated prerecorded information from which the user can select the key offered to choose the relevant topic (Kassavou & Sutton, 2018; DeSouza et al., 2014). IVR platforms have multiple navigation features to interact with callers or prompt callers to engage in recorded interactive dialogues, either through voice input or phone keypad selection (Kassavou & Sutton, 2018).

mHealth can be delivered through mobile telephony (Qiang et al., 2011), whereby “even a simple one-to-one telephone call may be effective in helping the caregiver as a client” (Reinhard, 2016), and “cellular phone networks could be used to deliver call center services” (As-Saber & Hossain, 2019). These mobile phone services include

*personal calls* between caregivers and healthcare professionals that facilitate verbal communication (Corry et al., 2017), or through *an IVR system* (Vodopivec-Jamsek et al., 2012).

Public health services and healthcare facilities have been using *IVR* for several years, especially in illiterate populations with limited Internet connectivity (Gilroy et al., 2015; Thakore, 2014). IVR technology that offers education and behaviour change communication through mobile healthcare delivery (Tsoli et al., 2018; Labrique et al., 2013) is appropriate in resource-constrained environments, where smartphones are not available (Labrique et al., 2013). Healthcare delivery through either personal communication or automated platforms such as IVR (Vodopivec-Jamsek et al., 2012) is beneficial:

- In Ghana, caregivers of sick children could access an IVR helpline and seek help based on disease symptoms (Brinkel, Dako-Gyeke, et al., 2017), and receive tailored feedback.
- Caregivers in a study by Mahoney et al. (2003) were exposed to an IVR intervention that delivered information about stress monitoring and counselling through weekly conversations. The IVR system was operated by a computerised human voice provided by a radio presenter known in the community.
- Aponjon, an IVR system used by pregnant women or new mothers in Bangladesh, resulted in increased knowledge, improved practices, and positive behaviours in this population (Chowdhury et al., 2019; Istepanian & Woodward, 2017).
- Some other views related to the importance of IVR voice services are gender preferences for the voice used (Shet et al., 2014), voice tone, that is, whether it is friendly, encouraging, motivated, courteous, respectful, and cheerful (Ames et al., 2019), and a reassuring tone of recorded voice (Murthy et al., 2019).

A more natural conversation is sometimes preferred over an automated voice delivering pre-recorded content. Mobile phones offer communication through various

formats, including more personalised ways, such as calling a healthcare professional for support.

### **3.5.4 Helplines**

An additional pathway to delivering healthcare could take the form of communication helplines that provide information services to the caller. It is preferable that callers access the helpline from their own homes, and on their terms. This creates a comfortable milieu in which they can confidentially ask for information and advice in the safety of their homes. Phoning is less time-consuming than a personal visit because the caller does not have to travel to obtain help. *Helplines* provide support to caregivers through an actual conversation with a healthcare professional who offers assistance and conveys the feeling of being cared for (DeSouza et al., 2014; Howe et al., 2014; Chavan et al., 2012). A nurse usually operates helplines and receives more inbound calls than making outbound calls. The helpline can successfully deliver healthcare information, do consultations, prevent disease, and educate people according to the needs of the caller (Kaminsky, 2013; Nauright et al., 1999) by using mHealth technology. Due to high mobile phone penetration, a *helpline* call service could reach large populations in hard-to-reach geographical areas with poor healthcare access (Ivatury et al., 2009). Limited human healthcare resources, transportation shortcomings, and unskilled caregivers in LMICs could benefit from helpline call services (WHO, 2018a; 2018b; Earth Institute, 2010).

Helplines should be accessible when other healthcare services in the community are closed. Helpline staff members should keep callers' culture, religion, and socio-economic status in mind when assisting individuals (Woodward & Wyllie, 2016). Helplines could limit stigma and maintain confidentiality in mental healthcare (Chavan et al., 2012). Delponte et al. (2015) reviewed literature related to ITC in the developing world that found helplines and toll-free services to be reliable interventions in LMICs. Some examples of such initiatives are the following:

- Project Masiluleke's "Please Call Me" initiative in the fight against HIV/AIDS and tuberculosis in South Africa connected users to government helpline

centres so that they could obtain information that was culturally relevant, in several local languages (UNICEF, 2017).

- Chipatala Cha Pa Foni (CCPF) is a toll-free helpline that offers pregnant and childbearing women and caregivers of young children health information, advice, tips, and reminders via SMS messages, or users can call the toll-free helpline with a specific code (Crawford et al., 2014).
- In South Africa, Deysel (2017) assessed a national non-profit organisation call centre with 13 mental health helplines that offered assistance through trained volunteers. Her findings indicate that callers required information and support and were conscious of help-seeking behaviour.

As a rebuttal to this topic, some evidence seems to suggest that *helplines* could be demanding on resources and challenging to sustain, compared to an IVR system (DeSouza et al., 2014). High airtime costs prevented users from calling for help or from getting information, although they appreciated receiving calls from healthcare professionals that took the time to engage with them (Watkins et al., 2018). In another study, participants preferred to use voice functioning rather than text messaging (Zurovac et al., 2013), while Head et al. (2013) found that text-only interventions or with other extra functionalities, e.g., human counsellors, did not differ in effectiveness. However, a review by Ames et al. (2019) draw our attention to their finding that participants preferred full-text messages, rather than “text speak messages”, though Oksman (2010) established that calls could sometimes be heard by others nearby, while text message content could not be seen by others. SMS or MMS are valuable functions of mobile phones; though mobile applications are also worth mentioning in mHealth initiatives.

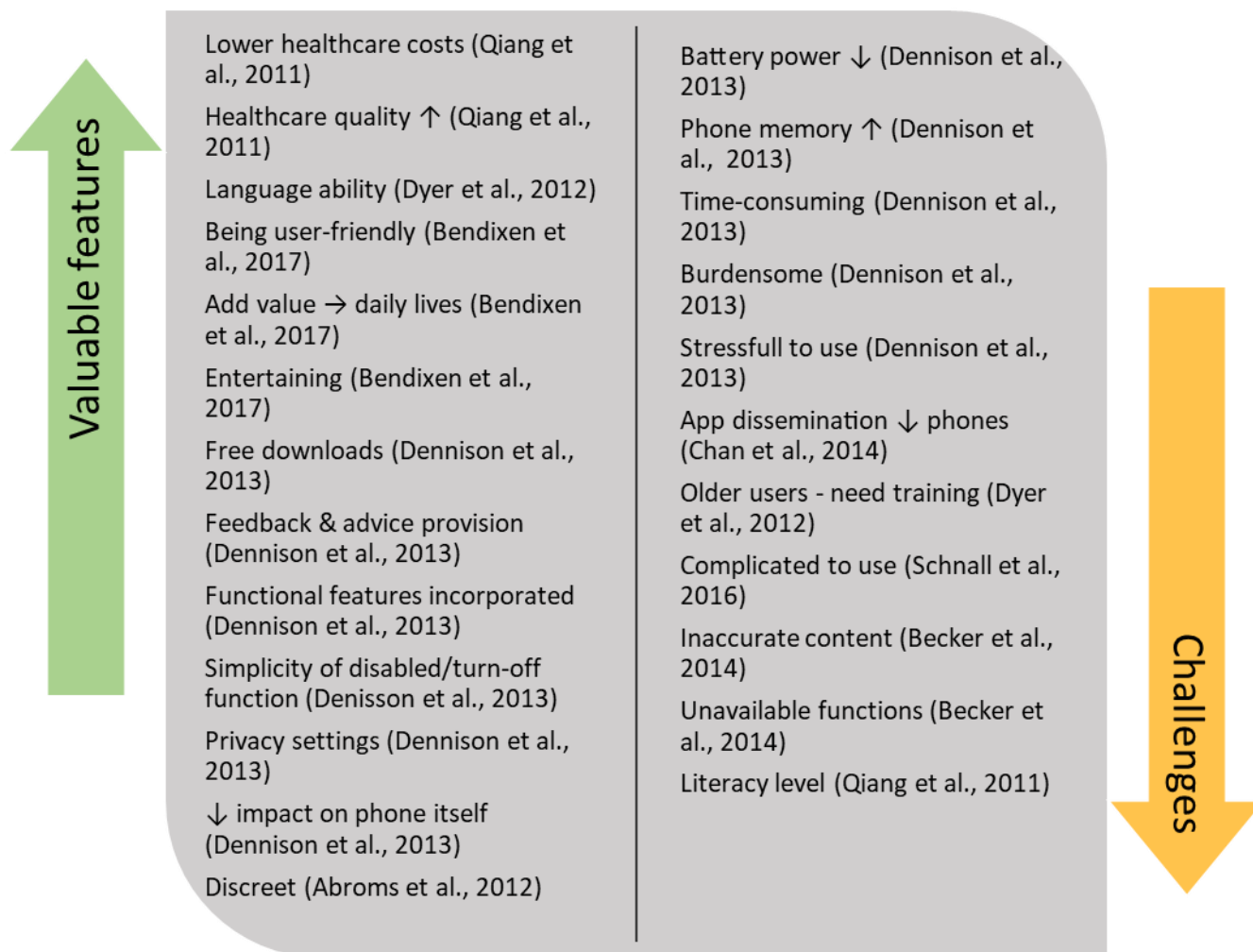
### **3.5.5 Mobile applications**

The content format of text messaging, multimedia, and interactive platforms, such as applications (apps), differs. A mobile app is software that connects the user with the content through various functions (Bendixen et al., 2017; Scolari et al., 2012). According to Scolari et al. (2012) – “applications are becoming more than just tools for doing: they are also involved in distributing contents”. In other words, apps take part in the “knowing process.” An app is user-friendly in that it does not require

access via an Internet browser (Woodard et al., 2014; Scolari et al., 2012) and is accepted as a practical initiative to provide healthcare (Payne et al., 2015; European Commission, 2014). Basic mobile phones consist of embedded apps, such as SMS and calendars, while smartphones can run complex apps, including WhatsApp, that can manage multifaceted healthcare (Baig et al., 2015; Woodard et al., 2014; Klasnja & Pratt, 2012).

Exponential growth and diffusion have transpired in the mobile healthcare app arena (Dyer et al., 2012), especially in LMICs. A shortage of skilled healthcare professionals in these countries set the stage for mobile apps due to their accessibility and continuous availability. *Mobile apps* can supply essential healthcare knowledge to the user in resource-constrained areas at convenient times (Royston et al., 2015; Malvey & Slovensky, 2014; Danis et al., 2010). The potential of mobile apps in rural healthcare is enormous (Laidlaw et al., 2017; Chand et al., 2016; World Bank, 2012) for advancing healthcare and providing support, advice, information, training, reminders, interaction, decision-making, health monitoring and encouragement (Jusoh, 2017; Dennison et al., 2013; Barton, 2012; Klasnja & Pratt, 2012).

A review by Dyer et al. (2012), on mobile applications to support non-professional caregivers, commonly found the following types of applications: education modules, self-care, peer-to-peer communication, and application tools to improve communication between caregiver and healthcare professional. With this in mind, caregivers should be involved when planning or designing mobile applications. Their needs ought to be the “building blocks” during the “architecture” of mHealth initiatives. Therefore, developers must consider the possible value and challenges related to mHealth apps (Becker, 2016; Schnall et al., 2016; Chan et al., 2014; Dennison et al., 2013) **Figure 3.4** provides a summary of the valuable features of and challenges facing apps.



**Figure 3.4: Apps: Valuable features and challenges**

It is essential to gain more in-depth insight into the value of and challenges facing applications, mainly to understand the interactive possibilities that enable the targeted population to use it. The efficient employment of the app depends on the literacy level (health and ICT) of the targeted population, in this case, caregivers, to engage with the app as well as the mobile phone itself (Corralejo & Domenech Rodríguez, 2018; Bakker et al., 2016; Qiang et al., 2011). Correspondingly, adoption of mHealth applications may help caregivers to “become better informed and proactive in help-seeking services” (Qiang et al., 2011). Jusoh (2017) states that mHealth apps should inspire end users to gain health information and achieve mental well-being through healthier behaviours.

mHealth applications targeting mental well-being can be advantageous, due to their effectiveness (Bakker et al., 2016), thereby making it possible for caregivers to access applicable information that can support them (Chan et al., 2014), and motivating caregivers inherently to change their behaviour to more positive behaviour after being empowered by the information they acquired (Free et al., 2013). mHealth features include various applications, namely SMS, MMS, and other software applications (Free et al., 2013) that can support end-users' behaviour on a range of topics, from family planning to illness promotion and advice (Källander, 2010).

### **3.6 CHAPTER SUMMARY**

This comprehensive literature review offered diverse inventories for improving understanding of communication technology and related concepts. The chapter delved into knowledge domains of eHealth, mHealth, their benefits and barriers, as well as caregivers' readiness to adopt mHealth initiatives. Information on relevant legislation added to the contextual discussion of the mHealth landscape. Features of mobile phone technology, including messaging, call services, helplines and mobile applications, were explored as promising tools that could support rural caregivers. Gaining insight into these concepts and relevant domains provided an evidence-based platform to motivate framework development for an mHealth initiative.

Finding a "one size fits all" mHealth strategy will be challenging. Socio-economic diversity in different countries and regions cause different mHealth engagements. Low-income countries engage less with mHealth activities than high-income countries do. Overall, European countries participate most in mHealth activities, while African countries are the least involved. With this in mind, we should remember that some African countries still experience a lack of electricity, a great deal of poverty, high illiteracy levels, and geographical challenges, even though there is a high penetration of mobile phones (Malvey & Slovensky, 2014). Human resource and disease challenges in healthcare contribute further to poor health outcomes among the public. Indeed, it is likely that mHealth technology can support caregivers and rural communities to deliver healthcare when required (Free et al., 2013; Danis et al., 2010).

## CHAPTER 4: INTEREST IN COMMUNICATION TECHNOLOGY BY RURAL CAREGIVERS OF ADOLESCENTS WITH MENTAL HEALTH ISSUES IN SOUTH AFRICA: THE MMOGO-METHOD®

### 4.1 INTRODUCTION

This chapter will present an article that explores rural caregivers of adolescents with mental health issues in South Africa's interest in communication technology, by applying the Mmogo-method®.

### 4.2 MANUSCRIPT DETAILS



Title	Interest in communication technology by rural caregivers of adolescents with mental health issues in South Africa: the Mmogo-method®
Authors	Ronelle Jansen and Marianne Reid
Journal	<i>Issues in Mental Health Nursing</i> (Taylor & Francis online)
Journal details	International Open access Peer-reviewed journal Listed as an accredited journal by the Department of Higher Education and Training (South Africa) Impact factor 0.977 (2018 Journal metrics) <a href="https://www.tandfonline.com/toc/imhn20/current">https://www.tandfonline.com/toc/imhn20/current</a>
Status	Accepted for publication
Author guidelines	<a href="https://www.tandfonline.com/action/authorSubmission?show=instructions&amp;journalCode=imhn20">https://www.tandfonline.com/action/authorSubmission?show=instructions&amp;journalCode=imhn20</a>

### 4.3 ASSOCIATED ADDENDA

Addendum B (HSREC), Addendum C (Department of Health) and Addendums E refers to the information leaflets and informed consent forms used during this phase.



## Interest in Communication Technology by Rural Caregivers of Adolescents with Mental Health Issues in South Africa: The Mmogo-Method<sup>®</sup>

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### ABSTRACT

Caregivers determine the level of care adolescents with mental issues receive; however, caregivers' own needs are often unmet. Communication technology can be tailored to address these challenges, especially in a rural environment. This study aimed to explore caregivers' interest in using communication technology to provide support to address challenges. This study involved a visual-based narrative inquiry that gathered data through the Mmogo-method<sup>®</sup>. Three (n = 3) groups were held with rural caregivers (n = 17) of adolescents with mental health issues in a rural area in the Free State province of South Africa during 2017. Three themes captured challenges confronting caregivers, namely, psychosocial, social resources, and informational challenges. Interest in communication technology was captured in a fourth theme. The findings indicate that communication technology can address caregivers' challenges by providing support and information to caregivers in rural areas. Communication technology, including mobile phones, electronic devices, and the Internet, has transformed healthcare services and proved to be valuable in resource constraint environments.

### Introduction

There are only four kinds of people in the world –

Those who have been caregivers,

Those who are caregivers,

Those who will be caregivers and

Those who will need caregivers

–*Rosalynn Carter* (Carter, 2018)

Adolescents make up about a quarter of humanity: Young people between the ages of 15 and 29 number about 1.8 billion (Commonwealth Secretariat, 2016) and adolescents aged 10–19 represent 1.2 billion of this population (World Health Organization, 2017). The vast majority (90%) of these adolescents live in less developed countries of the world, including Africa (Commonwealth Secretariat, 2016). In South Africa, at the southern tip of sub-Saharan Africa, 37% of the population is young people. The implications of this demographic trend relate to potential risk factors for adolescents' mental health and well-being. Typical determinants of mental health are psychological, social, cultural, economic and environmental in nature, such as diversity, inequity, substance abuse, violence, crime, poverty, genetic vulnerability and stressful events—all these factors contribute to mental health issues among adolescents in South Africa (Kieling et al., 2011; NYDA, 2015; Paruk & Karim, 2016). These issues, if left untreated may develop into a mental health disorder. More common mental health disorders among

adolescents in South Africa are depression, anxiety, substance abuse and self-harm (Kleintjes et al., 2010; Mfidi, 2018).

The terms 'mental health issues', 'mental health problems' and 'mental health disorders' are used interchangeably in academia. For the purpose of this article, mental health issues will be indicative of emotional and behavioural problems that do not meet all the criteria of a mental health disorder. Mental health issues make adolescents vulnerable to developing acute and chronic diseases, such as mental health disorders and other health and developmental problems (Patel et al., 2007), which may also affect adolescents' families. Families' needs regarding recognising and managing mental health issues, and which are unmet, should be addressed by health services worldwide (Das-Munshi et al., 2016; Fisher & Cabral De Mello, 2011; World Health Organization, 2017). There is a need to improve mental health outcomes by reorganising and strengthening mental health services.

South Africa has reengineered a comprehensive primary healthcare (PHC) approach, so that it integrates mental health services at a PHC level (Dookie & Singh, 2012) by shifting care from mental health institutions, to PHC provided in communities (Shen et al., 2017). The PHC system has assumed responsibilities for which it is poorly equipped, due to an extensive burden created by deinstitutionalisation. Burdens include human resource shortages and an unequal workforce distribution between urban and rural areas (Alzahrani et al., 2017; Jiloha & Kukreti, 2016), which have

a detrimental effect on mental healthcare and treatment (Abdulmalik & Thornicroft, 2016; Kakuma et al., 2011).

South Africa's government adopted a task-shifting approach to address gaps in mental healthcare, especially in rural settings (Mijovic et al., 2016). Task shifting is defined as "the delegation of tasks or responsibilities" between various healthcare professionals or between healthcare professionals and lay persons in the community, who act as caregivers (Kakuma et al., 2011). In practice, task shifting means shifting healthcare responsibilities to family members, relatives, neighbours, school teachers or healthcare workers (Alzahrani et al., 2017; Jiloha & Kukreti, 2016). Characteristically, these caregivers are not professionally trained, receive no payment, and have no working contract or specified working hours (Colombo et al., 2011). In South Africa, it is common for children in rural communities to live in female-headed households (usually with the mother as primary caregiver), or in the care of other relatives, who have to care for more than one child (Hall & Sambu, 2017). Caring for people with ill health is a difficult task that affects caregivers' daily lives emotionally and physically (Bauer & Sousa-Poza, 2015), since caregivers are responsible for a variety of tasks in the home setting at all hours of the day (Fernandes & Angelo, 2016). Nevertheless, task shifting is said to promote effective, integrated care in the community (Crowley & Mayers, 2015).

Caregivers of adolescents face particular challenges, because, unlike a physical illness with clear-cut signs, mental health issues are not easy to identify or observe (Patil et al., 2016). People who undertake this caregiving role in resource-constrained settings feel challenged and unsupported (Marimbe et al., 2016; World Health Organization, 2017). Caregivers lack essential knowledge (Frauenholtz et al., 2015), experience isolation (Mwei, 2015), exhaustion (Bauer & Sousa-Poza, 2015) and stigmatisation (Hawes & Allen, 2016) are required to manage medication and symptoms (Brazil et al., 2014) and seek expert information from professionals (Tilahun et al., 2016), and may have negative feelings towards the adolescents in their care (Hawes & Allen, 2016).

A clear understanding of caregivers' challenges is needed to bridge the gap between caregivers' unmet needs, and the mental healthcare needs of adolescents. This understanding is a key step in finding a way to support caregivers and, in so doing, to enhance the mental health outcomes of affected adolescents (Kuhn & Laird, 2014; Semrau et al., 2016). Initiatives to support caregivers are necessary to ensure meaningful behavioural changes in their caregiving practices. Their local contexts, cultures, traditions and values are relevant (Semrau et al., 2016). It is, therefore, important to plan, implement and sustain tailored approaches that are effective in supporting caregivers (Viana et al., 2013); it is also vital to incorporate evidence of effective delivery platforms in designing such initiatives (Shidhaye et al., 2015).

The advent of communication technology has augmented possibilities to improve people's health worldwide, including prevention, diagnosis, treatment and research regarding conditions. Simply put, communication technology can provide healthcare services remotely using mobile phones, electronic devices and the Internet (Davis et al., 2016).

Communication technologies are increasingly being used as healthcare interventions (Ben-Zeev, 2016) and are able to bridge gaps in health service delivery in rural areas (Varshney, 2014). These possibilities include the management of mental health disorders in low and middle-income countries (LMICs) (Naslund et al., 2017). Because of an increase in mental health issues, and an escalation of communication technology development in LMICs, there is a nascent field for scaling up mental health service delivery (Hilty et al., 2017; Lund, 2017; Naslund et al., 2015).

Several studies have identified the clinical promise and acceptability and feasibility of using technology to communicate with people with mental health issues (Ben-Zeev, 2016) and with healthcare providers (White et al., 2016). However, there is still inadequate evidence available on mobile health interventions for non-communicable diseases in sub-Saharan Africa (Opoku et al., 2017) as well as on carer-focussed interventions for mental health issues (Yesufu-Udechuku et al., 2015). Considering that 88% of South African households, and 90% of those in the Free State province, have access to at least one cellular phone (Statistics South Africa, 2017), we could assume that communication technology may be a convenient alternative solution to providing support to rural caregivers.

Quite a number of evidence-based interventions and programmes focussed primarily on caregivers of people with dementia (Charles et al., 2017; Hughes et al., 2017; Meyer et al., 2017). In contrast, there is inadequate research on how caregivers perceive mental health issues of children, and what kinds of support, facilities, service delivery and help these caregivers desire (Patil et al., 2016).

Severe shortages in the health workforce, health disparities, underfunding and underutilisation of health services in rural communities of LMICs necessitate the implementation of affordable, personalised communication technology (Farrington et al., 2014; Naslund et al., 2015; Schrader et al., 2014). It is crucial to be mindful of the preferences of end users, because their interests will determine whether they will use communication technology (Chigona et al., 2013; Thondoo et al., 2015). Several research studies have suggested that caregivers' interest in using communication technology will result in better health outcomes for care recipients (Bendixen et al., 2017; Lu et al., 2017; Park & Kwon, 2018; Ploeg et al., 2017). Researchers have campaigned for an integrated communication technology platform for mental health issues, to address mental healthcare challenges in various settings (Farrington et al., 2014).

Against this background, the researchers explored whether rural caregivers of adolescents with mental health issues in South Africa are interested in using communication technology to obtain support, so that they can address the challenges they face.

### *Theoretical framework*

The Integrated Model of Behaviour Prediction (IMBP) formed the theoretical underpinning of the study. According to the IMBP theory, behavioural intentions of the target

population are predicted by determinants such as their attitude, subjective norms and self-efficacy towards performing specific behaviour. These IMBP determinants may also be influenced by a lack of skills or environmental constraints as well as the target population's background (Fishbein & Yzer, 2003). Favourable outcomes will follow if the individual's intention to perform the given behaviour is influenced by a positive attitude and self-efficacy (Fishbein & Cappella, 2006). This study set out to determine whether rural caregivers in a resource constraint environment have the intention to use communication technology as a supportive initiative in their caregiving behaviour

## Methods

This study employed a visual-based narrative inquiry (VNI). Narrative inquiry is also associated with research indigeneity, in which storytelling occurs through visual, performative and textual practices (Kovach, 2018). The expressive potential of VNI depends on participants being actively involved through both their visual constructions and storytelling (Edmonds et al., 2016; Emmison et al., 2012).

This study used the Mmogo-method<sup>®</sup> to construct visual data. Vera Roos, a community clinical psychologist, developed the Mmogo-method<sup>®</sup> from the Indingilize Structured Observation Technique. In collaboration with two Setswana-speaking colleagues and psychologists, it was decided to name the new method "mmogo." Mmogo in Setswana (an African indigenous language) means 'building together' and 'as one'. The Mmogo-method<sup>®</sup> is a culture-sensitive projection method that can be used to gain insight in participants' unconscious thoughts, and which appreciates the cultural symbolism that informs behaviour. The Mmogo-method<sup>®</sup> engages individuals in a discussion that resembles an 'indigenous' focus group, though it uses individual visual constructions as a point of reference to discuss participants' perspectives collectively. The groups are arranged to consist of, ideally, between six and 10 members (Chigeza et al., 2013; Hanson, 2012; Roos, 2008).

In the Mmogo-method<sup>®</sup>, participants create visual constructions through materials that symbolise their culture, such as clay, grass stalks and differently coloured beads or buttons. Participants are arranged in a circle and selected material is provided to each person, who each gets an opportunity to create visual constructions after a prompt from the facilitator. Each participant's construction is used to stimulate group discussion (Roos, 2016; Shabangu, 2011). A group discussion related to participant-generated visual constructions elicits authentic narratives that also reflect the 'unsayable' (Schneider & Kayseas, 2018). The Mmogo-method<sup>®</sup> generates multiple sources of data. In addition to the participants' constructions (visual data), audio recordings of individual and group discussions (textual data), observations, and researcher reflections can be generated (Clarke & Braun, 2013; Roos & Redelinghuys, 2016). Visual research deploys text and images analytically to exploit narratives of participants' interpretations associated with the research question (Banks, 2007). Holstein (2018) claims that

interpretation and analysis of narrative representations can be powerful, while Switzer (2018) state that collecting and analysing visual data create opportunities to acknowledge unspoken stories.

The method consists of four phases. In phase one, the facilitator creates the context by setting the scene and introducing group norms. In phase two, each participant receives a lidded plastic container containing selected materials, and the facilitator asks an open-ended prompt relevant to the proposed research. In phase three, the facilitator asks a volunteer participant to explain their construction to the group and, thereafter, encourages a group discussion. The discussion is audio recorded. In turn, participants are given the opportunity to share their constructions. Photographs are taken of the visual constructions, and serve as data. During phase four, the facilitator debriefs the participants and gives them the opportunity to give feedback about their impressions of the session (Roos, 2016).

## Ethics

Ethical approval (HSREC 47/2017 (0349) and relevant institutional approval (Free State Department of Health) was received. All participants provided written informed consent prior to participation in the study and gave permission to publish the photographs.

## Context of the research

The study was conducted in the Kopanong Municipality, which is situated in the Xhariep district, in the Free State province of South Africa. The Xhariep district is a rural, sparsely populated area. Kopanong Municipality, consisting of nine towns, covers the largest section of the Xhariep district. The community includes a diverse population of Black Africans (72%), Coloured people (17%), White people (9%) and Asian people (0.04%). The main languages are Sesotho, Afrikaans and isiXhosa. Young people (<35 years) represent almost 69% of Xhariep district's population while children below 18 years represent 33%. Some vital concerns that affect the youth in this community are a high school dropout rate, lack of life and technical skills, and alcohol and substance abuse (NYDA, 2015; Xhariep Municipality, 2011). In Kopanong Municipality, 38% of households are female-headed, and have an average size of three members per household (Matwa, 2015). Most of the people who live in poverty in the Xhariep district, reside in the Kopanong Municipality (Kubeka, 2016).

## Participants

The population consisted of caregivers of adolescents with mental health issues in the nine towns of Kopanong Municipality. Initial convenient sampling of two towns (Trompsburg and Springfontein) led to purposive selection of participants (n=17) through an already established network of stakeholders. Participants were included if they were the primary caregivers of adolescents who presented

**Table 1.** Characteristics of participants (n = 17).

<b>Gender:</b>	
Male	1
Female	16
<b>Age:</b>	
Range: 34-74 years	
<b>Relationship with adolescent:</b>	
Uncle	1
Mother	8
Grandmother	4
Aunt	3
Cousin	1
<b>Main source of income:</b>	
Government grant	7
Pension	5
Employed	3
Family support	1
No income	1
<b>Highest level of education:</b>	
Primary school	3
Secondary school	11
No schooling	2
Not stated	1
<b>Owning a cell phone:</b>	
Yes	12
No	5
<b>Cell phone expenses/month:</b>	
R0-R90	5
R100-R200	7
Not applicable	5

with mental health issues, and if they agreed to participate in the research. An overview of the participants' characteristics is provided in Table 1, and of the adolescents being cared for by participants, in Table 2.

### Data collection

Gatekeepers, who comprised of community care workers and school employees from the Kopanong Municipality, assisted in identifying participants who met the inclusion requirements. A pilot study (n = 7) in Trompsburg indicated that the research prompt (question) should be refined. Participants from the pilot were not included in the main study, and neither was the data they had provided included in the final results. Three groups were conducted on three separate days in September 2017: Group 1 (n = 7) in Springfontein, Group 2 (n = 4) in Trompsburg and Group 3 (n = 6) in Springfontein. Data saturation was reached after the third group.

The four phases of the Mmogo-method<sup>®</sup> were applied to every group discussion. All three groups preferred to speak Afrikaans and a community care worker interpreted if participants wanted to express themselves in another language. The participants received a plastic container with malleable clay, grass stalks, coloured match sticks and differently coloured beads. The researcher, as the facilitator, gave participants an open-ended prompt in Afrikaans, translated as 'Please make a picture that depicts the relationship between yourself and the adolescent with the mental health issue you care for'. The researcher followed cues related to advice, information or knowledge voiced by the participants during

**Table 2.** Characteristics of adolescents being cared for by participants.

<b>Gender:</b>	
Male	15
Female	2
<b>Age range:</b>	
13-19 years	
<b>School grade:</b>	
Grade 7	1
Grade 8	4
Grade 9	3
Grade 10	4
Grade 11	4
Grade 12	1

*Mental health issues:* Inattention, do not listen, naughtiness, hyperactive, slow learner, substance use (cannabis, alcohol and glue), school truancy, comes home late, sleeping out, schoolwork declined, attitude (cheeky).

the discussions to probe their interest in communication technology further.

### Data analysis

Audio recordings were transcribed verbatim and translated into English. The researcher and a co-data analyst independently implemented a thematic analysis approach for the *textual data* (audio recordings), as proposed by Clarke and Braun (2013). This analysis took place through a recursive process of six steps, namely, familiarisation, data coding, searching for similar themes, reviewing themes, defining, naming, and writing themes up. The facilitator and co-analyst analysed the visual data (photographs) further, independently, according to the 6-step analysis developed by Roos and Redelinghuys (2016) which involves describing the research context, assuming an empathic stance towards data, describing the literal observations of the visual elements and symbolic meanings attributed by the participants, describing participant-introduced context and, lastly, conducting an explanatory analysis. The researcher and co-analyst, together, triangulated themes emerging from textual data (audio recordings) and visual data.

### Rigour

The facilitator was mindful to maintain the contextual sensitivity of the data, and verified meanings through member checking throughout each group discussion. The Mmogo-method<sup>®</sup> provided a rich set of data that extended our understanding of the participants' challenges in a resource-poor environment and their interest in communication technology.

### Results

The unstructured nature of the open-ended prompt guided the participants to construct subjective interpretations. In the Mmogo-method<sup>®</sup>, the researcher should assume an empathic stance and clarify meanings (Roos, 2008). In this study, the researcher, first, explored the conspicuous context introduced by the participants (caregiving challenges) and, through reflective questioning, explored their views

**Table 3.** Themes and subthemes.

Themes	Sub themes
1. <i>Psychosocial challenges</i>	<ul style="list-style-type: none"> <li>• <i>Well being</i></li> <li>• <i>Roles</i></li> <li>• <i>Beliefs</i></li> </ul>
1. <i>Social resource challenges</i>	<ul style="list-style-type: none"> <li>• <i>Personal control</i></li> <li>• <i>Relationships</i></li> <li>• <i>Support services</i></li> <li>• <i>External challenges</i></li> </ul>
1. <i>Informational challenges</i>	<ul style="list-style-type: none"> <li>• <i>Resources</i></li> </ul>
1. <i>Communication technology</i>	<ul style="list-style-type: none"> <li>• <i>Behavioural issues</i></li> <li>• <i>Interest</i></li> <li>• <i>Preference</i></li> </ul>

regarding the use of communication technology. The results were contextualised according to these two elements.

Evidently, participants enjoyed working with their hands. Doing so instinctively gave them opportunities to 'show' their perspectives without any further prompting by the facilitator. The thematic analysis of the textual and visual data led to four main themes and relevant subthemes. Table 3 illustrates the themes and subthemes that are described in this section. Unedited illustrative quotes are used as examples from the participants' 'own voices'.

#### ***Psychosocial challenges (theme one)***

In this theme, four subthemes emerged that explain the psychosocial challenges that participants experienced in their caregiving. Caregivers in all three groups talked about emotional **well-being**. Emotional well-being is associated with caregiver burden, and the participants portrayed an array of emotions. The researcher observed this emotional strain in the congruence of their verbal and non-verbal behaviour. One participant said,

I don't feel well and my heart is very dry.

This participant illustrated this sentiment through the symbolic use of grass stalks, which resembled "a bare tree" in her picture. Other participants demonstrated their sadness and heartache with 'clay hearts with sticks inside' or 'heart shapes with beads'. Participants also acknowledged their anger towards these adolescents through the following quotes:

I want to scream.

When I talk to them, they know I want to fight.

Other emotional responses expressed during the discussions were worry, frustration, despair, wanting to cry, hopelessness and helplessness. They expressed these emotions through different colours in their constructions. However, participants stated that they still have hope, which was embodied through their religious beliefs.

Caregivers are responsible for balancing a variety of roles, such as parent, spouse, provider, caregiver and housekeeper. Caregivers described their caregiving roles as demanding, because of the adolescents' negative behaviour towards them. A general feeling was that they provide the adolescent with food, clothes, a bed, and a house to stay in, and they

polish their shoes. Several participants exhibited this thought by making houses with grass stalks, or created a representation of a house setting and/or food-related items in their pictures. One statement was,

I care for the child. Iron his clothes and gives him warm water.

Nevertheless, these 'children' do not help the caregivers in the house or appreciate their care. The participants were frustrated by the adolescents' apparent lack of appreciation for these tasks. Some participants were ambiguous and said they felt sorry for these children, because their own parents do not want them.

Participants in all three groups expressed strong convictions about their religious belief systems. Support through religion is traditionally acceptable in the participants' community, and it is embedded in their culture. It was evident that the participants valued their religion as vital for their role as caregiver. Their religious beliefs and participation created an emotional equilibrium that gave them comfort. One explanation was,

A person is happy in the heart if he goes to church.

These religious beliefs, however, surfaced only during the discussions, and were not portrayed in visual presentations.

The personal control of the participants was challenged by the adolescents' behaviour, to such an extent that caregivers wanted to smack the adolescents, or chase them away. Caregivers experienced loss of self-control and, perhaps, powerlessness. This loss of control led to the possibility of adverse relationships with the adolescent. Caregivers saw discipline as part of their caregiving role. This opinion was shared in all three groups. A few participants demonstrated this idea visually, by using grass stalks as 'sticks' that symbolised corporal punishment. An illustrative quote is the following:

I am going to hit him because he doesn't want to listen.

Disciplining the adolescents obviously presented a challenge and the adolescents' behaviour contributed to caregivers' feelings of helplessness, which caused psychosocial distress in the participants.

#### ***Social resource challenges (theme two)***

This theme generated three subthemes, that is, relationships, support services, and external challenges. Some participants did not experience family relationships and involvement as meaningful or satisfying. An underlying feeling was that shared decision-making and responsibilities could reduce the caregiving burden. Participants felt isolated and alone in the caring relationship. A descriptive comment was, for example:

His father's family does not want him and his mother's family does not want him.

A validation of the value of family relationships was provided by some participants. They confirmed the importance of a supportive family relationship and its contribution to the caring relationship. A participant said:

The house is a shelter, the family house.

Most participants constructed some form of housing, or the idea of a shelter, perhaps to express a sense of security for the adolescent, and as a way to show them that they care. Supplementary to this was the relational support from friends and peers in the community. A shared observation was that support from friends alleviated caregivers' sense of isolation and could be beneficial for everyone. One caregiver explained:

Getting advice from each other.

The participants explained the difficulties they experienced regarding support services in their immediate social environment, such as the police, school and clinic. According to their discussions, the police did not want to help them when they needed help. The law prohibits spanking, and participants had mixed feelings about this situation. They felt that their authority as caregivers was undermined, and they were desperate for assistance by the police. This situation created ambivalence about the role of the police. On the one hand, they said, "The police will hurt the children", and, on the other, "The police must come and put her in the van".

This uncertainty about the role of the police pointed to their vulnerability and powerlessness. Confirming this theme were comments by participants about schools. They agreed that the education system disappoints them, and offers limited support. They reminisced about the effectiveness of school discipline, extramural activities and parental information sessions, which are missing today. All three groups mentioned this as a concern. One participant said,

The school did not answer my questions.

They had mixed feelings about support services, such as assistance from healthcare professionals. One participant said that she received help from the professional nurse at the clinic. Another participant said the opposite:

Even when we talk to professionals they do not help us.

One other participant stated that she "seeks information from the adult people", meaning professional staff. This study obviously shows that participants recognised the importance and value of support from family members, friends, and healthcare professionals, both for themselves and for the adolescents.

The participants in all three groups complained about external challenges, namely, adolescents' peers, and adolescents' inactivity. Participants expressed various concerns regarding friends and peer pressure. Some said that friends had a bad influence on the adolescent, or that the adolescent spent more time with their friends than at home. It concerned the participants equally if the adolescents in their care were continually with friends, or alone without friends. Some of the remarks are the following:

He is always with his friends.

He used to have friends, but they are gone now.

Also related to this theme is the participants' view that the 'children' have nothing to keep them busy, as the schools do not offer extramural activities. Once again, they reminisced about how children used to participate in sports, handiwork and creative activities. They were of the opinion that, if the children are active and participated in extramural activities, they would not have time to be 'naughty'. Related to this concern, they believed there were insufficient resources in the environment to offer extramural activities. These factors were demoralising and caused the participants to be disheartened. Related statements are the following:

And the sportsgrounds are not operational.

There is no sport activities in the townships.

Against this backdrop, the researcher explored the caregivers' challenges in relation to their information needs and related support.

### *Informational challenges (theme three)*

In this theme, two prominent themes emerged, namely, resources and behavioural issues of the adolescents. All the groups mentioned the lack of resources to assist them as caregivers of adolescents with mental health issues, whether human or physical resources. There was an urgency in all the participants concerning their informational needs. A serious challenge that was identified was that participants needed information related to the adolescents in their care, and not knowing where to get the information. Some statements were,

We do not have advice.

We must get the information so that we know.

Although some participants believed "someone of the city must talk to them", others acknowledged that caregivers could support each other; this was affirmed by the following quote:

We can advise each other on how we can better deal with our children.

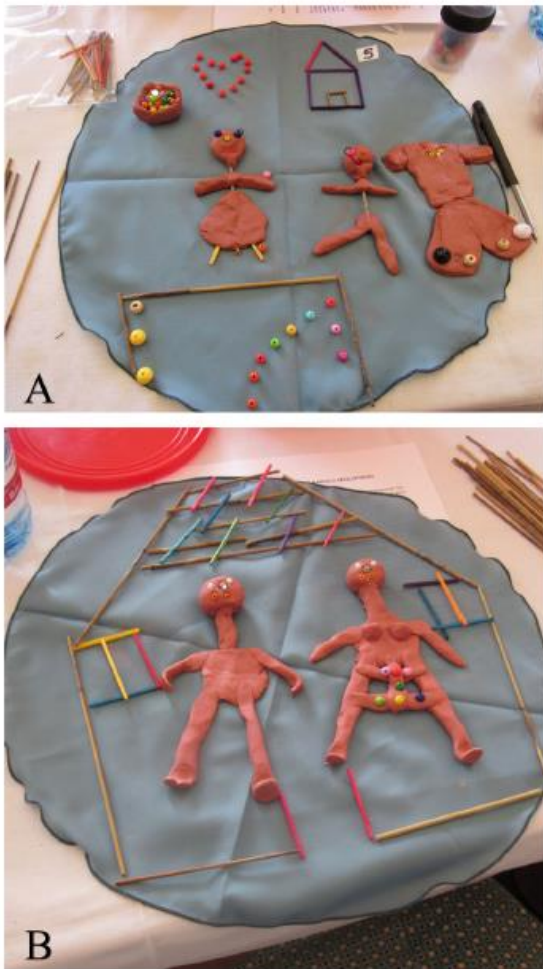
A participant said that she sometimes received advice from the radio and TV. Two groups discussed the value of religious principles for living. A typical statement was,

You listen to the words that is from the Bible.

All the groups reflected on their inability to understand the children's behaviour. Participants complained that the children smoked cigarettes and dagga (cannabis) and drank alcohol, but did not understand that this can possibly be a risk to the development of a mental illness. One participant claimed,

They are out of control.

Other concerns were related to poor school performance, failure to do homework, sniffing glue, walking around at night or sleeping out, and angry outbursts; this behaviour worried the participants. They appeared to consider this



**Figure 1.** Photograph A is from Participant 5 in Group 1: "This is my house. There is food and clothes for him. The house have some rules, but he does not follow it. I have a good heart for my child, but he does not listen. On a Sunday, we go to church, but he does not go. He only does wrong things. He smokes cigarettes and cannabis. I give him love, but he does not listen." (Caregiver on the left and adolescent on the right). Photograph B is from Participant 1 in Group 3: "This is my house. Every morning I give him clean clothes and polish his shoes. What is wrong in his head? I don't hit him. I don't know what to do! I made my eyes white because of all the crying. I made a dress and just made it beautiful with all the beads. But my heart is sad, I did not teach them these things." (Caregiver on the right and adolescent on the left).

behaviour as 'naughtiness', and not as part of a mental health issue or, possibly, a mental disorder. It was noticeable that participants emphasised their physical caregiver role, but did not explore their own role as an emotional caregiver. This failure demonstrated their inadequate knowledge of adolescents with mental health issues.

Significant was the use of red beads in the constructions of some participants. It symbolised the children's 'red eyes' when they smoked dagga or drank alcohol. Using colour or placing objects and shapes in certain ways did not otherwise indicate any particular meaning for most participants – it was just something that they decided on impulsively (and laughed about it when asked). See Figure 1 for examples of visual constructions and narratives.

#### Communication technology (theme four)

First, it was necessary to understand the aspects caregivers attached meaning to, namely, caregiving challenges, before the relevance of communication technology as a possible solution could be explored. The facilitator followed up on cues throughout the group discussions to probe their views regarding their *interest* in communication technology. Two groups indicated that they would like to receive information via cell phone. They selected SMS or phone calls as ways to send and receive information. The other group found information via computer useful. Two statements were,

Technology can work.

Computer in the public library can work.

No participant owned a desktop computer. Remarkably, all agreed that communication technology can be useful, but reacted negatively in relation to adolescents spending too much time using applications, such as WhatsApp and Facebook. This negative connotation could be the reason why participants preferred to receive information via SMS, phone calls or computers, and not through any social media platforms.

Seven participants indicated that they *preferred* to use SMS, and six preferred phone calls. Four participants did not indicate their preferences. Participants did not seem worried about using cell phones, or perceived themselves as unable to use it. They also mentioned that they would prefer that the school communicates with them via an SMS system, since the adolescents were unreliable about conveying messages. A number of participants expressed that it could be worthwhile to have something "like a SMS group" to support each other and share information.

The facilitator sensed a desperate need amongst participants for information that would guide them in their caregiving role. It was clear that participants enjoyed the group discussions, since they laughed a lot, and said that working with clay brought back nostalgic memories and relieved their stress. It was encouraging that participants in all three groups indicated a high sense of self-esteem, in spite of the challenges they faced with caregiving. They displayed good self-esteem through their visual constructions. The researcher got the impression that they wanted to prove their self-worth through the demonstration of some beauty in their constructions. Quite a few participants used coloured beads in their designs to reflect some form of self-praise. Typical remarks about their constructions were the following:

We are making beautiful things, watch and see.

I must make myself beautiful with the earrings.

They also praised each other's creations, for example, "You are making a beautiful illustration". They shared challenges freely, without any probing from the researcher. The researcher observed the caregivers' need to be recognised doing the best that they could under challenging circumstances.

## Discussion

Any planned initiative to support caregivers needs to address caregivers' identified preferences and needs (Hughes et al., 2017; Lambert & Girgis, 2017). Diverse initiatives that are contextualised and individualised could improve health outcomes for both the caregiver and care recipient (Bergström & Hanson, 2018; Frederick, 2016). The Mmogo-method<sup>®</sup>, as a VNI that is culturally sensitive, allowed participants to voice their concerns. Visual images provided a lens for understanding the research context and the profile of the participants (Balbale et al., 2014; Black et al., 2018). Evidence from the study signifies participants' interest in using communication technology to address their psychosocial, social resource and informational challenges.

### Psychosocial challenges

Participants in the current study subjectively and collectively identified various challenges that threatened their psychosocial *well-being*. They tried to understand what was going on with the adolescents under their care, whilst experiencing intense emotional pain related to the subjective burden they were carrying. The subjective burden refers to the way the caregivers' perceive the burden of caregiving, while financial, physical, and time constraints refers to objective burdens (Flyckt et al., 2015; Viana et al., 2013). No significant accounts linking to objective burdens, such as fatigue or lack of finances, transpired during the Mmogo-group discussions. In contrast, recent articles describe a decline in caregivers' physical health after entering the caregiver role (Pandey et al., 2019; Peterson, 2017) and unmet financial needs (Tilahun et al., 2016). Remarkably, even though the participants were from a socio-economically poor community, they were more troubled emotionally than financially or physically. Understanding the subjective burden in this context explains the caregivers' psychosocial challenges, which are aggravated by a lack of social support and information. Research studies shed light on the domains of supportive needs identified by caregivers, such as emotional needs (Brazil et al., 2014; Valery et al., 2015) associated with a caregiving burden.

Spiritual needs are also associated with a caregiving burden, and religion is seen as a way to cope with circumstances (Lambert & Girgis, 2017; Valery et al., 2015). The current study's findings are, thus, not unique, and are consistent with findings of previous studies. It is notable that the participants of Kopanong found more support through their religious *beliefs*, such as attending church and prayers, than from friends and family. These findings are supported by other research studies, which indicate that religion can provide the caregiver with the necessary strength to withstand the caregiver burden and to cope emotionally when caring for a family member with mental health issues (Smith & Milano, 2014; Taylor-Brown et al., 2014; Tilahun et al., 2016).

There is increasing acknowledgement that caregivers are overwhelmed by their *roles* and responsibilities, while trying to maintain their own well-being (Charles et al., 2017). To

compound the problem, the participants of Kopanong unconsciously expressed conflicting thoughts regarding their caregiver roles. These roles entailed more than just being the caregiver—they were also nurturers, housekeepers, spouses and providers. Conflicting roles augment additional burdens and responsibilities for the caregiver (Fernandes & Angelo, 2016), and a lack of resources contributes to their frustrations (Cady & Belew, 2017). In the current study, the participants also experienced role confusions, which led to negative behaviour, such as loss of control. It is worth noting that the majority participants were women, and that the adolescents were male. An earlier study by Bingham (2017) found that distribution of care is imbalanced, with female carers being responsible for the brunt of care. This role transition, from traditional nurturers to primary caregivers, caused challenges for the female participants of Kopanong. It is assumed that this situation caused struggles, and was the main reason for some of the caregivers' challenges. Similar findings describe the obstruction of the mother's autonomy by the power relationship between mother and the care recipient in rural communities (Bryant & Garnham, 2017). The presence or absence of male authority figures to assist in managing male adolescents never came up during the Mmogo discussions. The aforementioned could have caused the participants to experience powerlessness regarding managing adolescents with behavioural issues, leading the Kopanong participants to *lose control*. Kopanong participants held positive views about the effectiveness of corporal punishment, which is accepted by their cultural belief system, but realised that it is prohibited by the law. These findings are consistent with a survey of readers of the *Time* publication about spanking, in which almost 71% of respondents supported corporal punishment (Child Trends Databank, 2015; Taylor et al., 2016) and findings that American parents approved of corporal punishment, as part of their cultural beliefs (Chiocca, 2017). Researchers increasingly argue about the long-term emotional and behavioural implications of corporal punishment, and further research is needed to explore this controversial topic among different ethnic groups (Pandey et al., 2019; Streit et al., 2017). We can also argue that the Kopanong participants may have seen corporal punishment as a way of caring for the adolescent, and that they were uneducated about effective alternative disciplinary methods.

However, despite all these detrimental obstacles, the participants in this study displayed optimism. Their use of colour to represent beauty and praise in their pictures demonstrates some confidence in self-efficacy. The reasoning is that they believed that they deserved praise for doing a job well, and perceived themselves as capable of caring for the adolescents. Bandura (1990) refers to strenuous conditions that can influence a person's capabilities and self-efficacy. A person's belief that they are able to perform or apply behavioural control in difficult situations can increase their self-efficacy. He differentiates between having effective coping skills, and implementing it successfully under difficult conditions. Participants in Kopanong lacked self-control and skills, but believed that they were taking good care of

the adolescents. The authors of another study developed a hypothesised model in an attempt to improve understanding of self-efficacy in dementia family carers' practices. This model explains the link between individuals' characteristics and their effective adaptation in the caregiver role. The authors conclude that carer initiatives, including coping skills and psychoeducational methods, could improve the caregivers' self-efficacy and quality of life (Crellin et al., 2014; Taylor-Brown et al., 2014). Although most participants illustrated their own parenting efficacy through physical care and self-praise, it was evident that they did not realise that they were actually quite ignorant about caring for adolescents with mental health issues.

### Social resource challenges

The participants discussed *relationships* as part of the social resource challenges they endured. The caregivers experienced a sense of isolation from the family, and some reported that there were no familial relationships. Overall, they acknowledged the important role of family support within their cultural context, and some expressed their disappointment in this regard. This lack of family cohesion influenced the participants in a negative way and, consequently, also affected their well-being. The current findings confirm other studies, which report that parents of sick children (Pelentsov et al., 2015; Winskell et al., 2016) or caregivers of relatives with mental illnesses (Chang et al., 2016) need more social support from family and friends.

In addition to family isolation, participants were also isolated from *support services*, such as the community, the healthcare system and schools. This isolation should be discussed within the South African context, where social support is described as 'Ubuntu', which can be explained as African humanism: to be 'human through other people' (Mugumbate & Nyanguru, 2013). Clearly, caregivers in the Kopanong study did not experience this traditional approach to support. Many caregivers conveyed their disappointment in relation to support services; it appears that they blamed these services for some of their challenges. Their social expectations regarding the idea of 'Ubuntu' were unmet and reflected throughout the themes.

A combination of emotional and informational support provided by health professionals could support parents of children with special needs to improve children's health outcomes (DeHoff et al., 2016). Additionally, informational support might help parents gain insight into the adolescents' mental health issues, and lead to more positive outcomes (Kuhn & Laird, 2014). In contrast, most participants in the Kopanong study were pessimistic about whether they could depend on healthcare professionals for information. The caregivers experienced healthcare professionals as unapproachable, and the participants were frustrated. A related aspect is that healthcare services failed to support the caregivers as partners in the care relationship, which is an important aspect in a resource-poor environment (Cady & Belew, 2017).

Concerns were raised about the role of school systems, which should, to increase support, educate parents, relatives and caregivers on effective parenting skills (Duppung Hurley et al. 2017; Hoagwood et al., 2010). Further disappointment was expressed through Kopanong participants' opinions regarding the schools' role. They were dismayed that schools do not offer extracurricular activities, do not enforce discipline, and fail to inform caregivers about behavioural problems in a timely manner, or discuss it with them. The participants were adamant that the school should assist in providing education and training, and should involve caregivers concerning the mental health issues of the children in their care. Respondents in a study by Shen et al. (2017) valued the cooperation of the public sector, school, community and law enforcement, as key elements in mental healthcare.

This preceding outline may lend support to Kopanong participants' views that the lack of *external resources* in the community, as well as lack of extracurricular activities at schools, leads to mental health issues, such as drinking and using drugs. Extracurricular activities can prevent the use of these substances (Andrade, 2013) and Coto (2016) identifies the importance of extracurricular activities, such as fine art clubs, which could be protective factors for adolescent substance use. However, other researchers claim that involvement in sports can lead to substance use (Kwan et al., 2014; Veliz et al., 2015). The researchers in the present study did not attempt to determine a correlational or a causal relationship between extracurricular activities and substance abuse. The present study echoes previous work that confirms caregivers' high expectations regarding—assistance from schools or communities—expectation that are often not met (Choate, 2015).

### Informational challenges

Mental health awareness needs to be increased (Hanlon et al., 2014) and mental health issues among adolescents decreased (Helseth et al., 2016). Kopanong participants did not know where to get information about the mental health issues of adolescents, nor did they even realise that they needed information. It may be that caregivers considered mental health issues merely represented mischief; that they were actually ignorant about the seriousness of mental health issues that may become mental health disorders. Caregivers' ignorance can be addressed, and the more reason to criticise the lack of health information, *resources* and education provided by the PHC and schools in the Kopanong study. It seems that most Kopanong participants experienced no reciprocity in community partnerships. The overall burden increases when caregivers do not have support and information, or understanding of the illness or services available in the community (Coffey et al., 2017; Taylor-Brown et al., 2014).

The caregiver burden that was exposed by the present study corroborated participants' need for information, and also their lack of skills for the management of adolescents with *behavioural issues*. The participants did not comprehend the necessity for help-seeking, because they found it

difficult to recognise the 'invisible signs' of mental health issues. Over the past decade, reports about inadequate programmes in mental health prevention and promotion among adolescents have played an important role in research. Ultimately, a multicomponent mental-healthcare approach that includes awareness campaigns, community and school education, parenting training, and adopting evidence-based practices is needed to enhance adolescent and caregiver well-being (Hawes & Allen, 2016; Patton et al., 2016). This proposal can lead the way to solving the informational challenges experienced by participants in the present study, and guide them to obtaining timely help. Such approaches should extend to instituting and strengthening participants' skills, knowledge of and attitudes towards adolescents with mental health issues.

Moreover, the knowledge gap is justified, because Kopanong participants obviously lacked understanding of behavioural issues relating to the adolescents in their care. Primarily, some participants perceived the adolescents' behaviour as disrespectful and, due to the participants' inexperience about behavioural issues, criticised the adolescents' behaviour. The associations between family processes, parental behaviours and adolescent outcomes are well documented in literature. Parenting behaviours, such as ignorance, harshness, control and inconsistent disciplinary methods, may lead to delinquent behaviour (Gavazzi, 2011). Uneducated parents find it difficult to differentiate between delinquency and signs of mental health disorders (Kumar & Das, 2017). The Kopanong participants were struggling to cope with their daily lives and did not link the adolescents' behavioural issues to the possibility of mental disorders. Their educational background may have caused their lack of knowledge about mental health issues, causing them to be more vulnerable and dependent on a fragmented healthcare system.

### **Communication technology**

Salient communication technology initiatives have the potential to reduce caregivers' stress related to caregiving practices (Bergström & Hanson, 2018; Davis et al., 2016). Planned approaches that start with evaluating caregivers' risks, needs and preferences (National Academies of Sciences, Engineering, and Medicine, 2016) and caregiver participatory techniques in research (Semrau et al., 2016) will ensure the effectiveness of caregiver initiatives. Planning of initiatives should contextualise different needs, such as those of caregivers of adolescents with mental health issues (Mwei, 2015) and social-cultural values, traditions and rural-urban cultures (Semrau et al., 2016). The present study's objective accentuated using a bottom-up, and not a top-down, approach to explore an initiative that could possibly address challenges faced by rural caregivers of adolescents.

Various types of technology-based approaches, such as support groups, skills-building, and providing resources and education, could provide solutions to unsupported caregivers (National Academies of Sciences, Engineering, and Medicine, 2016). People living in rural areas, who have

limited access to support, may benefit from the application of information communication technology (Mwei, 2015; Nahar et al., 2017; Pimmer et al., 2017). The Kopanong participants acknowledged the importance of support. They concurred that they really would like to participate in support groups via WhatsApp or SMS, with the purpose of exchanging information and sharing experiences.

Communication technology is evolving as a prominent means to support and/or deliver healthcare. Mobile health (mHealth) and electronic health (eHealth) technologies are potentially powerful for the communication of information, especially in rural and poor communities (Brinkel et al., 2014; Farrington et al., 2014; White et al., 2016). Although using communication technology to obtain information presented no problems for most Kopanong participants, there were differences among the groups about preferences for the delivery mode. It was promising that the Kopanong participants saw the potential in communication technology, whether mobile or electronic. Also encouraging was the emergence of mHealth and eHealth technology use in the care of adolescents with mental health issues, and their caregivers (Chib et al., 2015), and to improve health outcomes in LMICs (Wallis et al., 2017). Evidence-based initiatives that are aimed at assisting caregivers could improve quality of life, alleviate distress, and relieve the caregiver burden (Flyckt et al., 2015; Yesufu-Udechuku et al., 2015). From the Kopanong findings it is evident that the participants were interested in accepting communication technology to deliver knowledge, skills and support regarding caring for adolescents with mental health issues in a resource-constrained environment. Before such an initiative is planned, participants' beliefs, attitudes and intention to use communication technology should receive attention.

Finally, considering that these participants were uninformed about mental health issues, it was crucial to explore their behavioural intention to get information. The Integrated Model of Behaviour Prediction (IMBP) supports the findings of this study to a substantial degree. The IMBP suggests that the individuals' attitudes, norms and self-efficacy will influence the performance of behaviour. The Kopanong participants demonstrated positive attitudes towards communication technology as a source of support and information.

### **Limitations**

Although all possible efforts were made to avoid disrupting group discussions, this was not always possible within a community environment setting. An example of such a disruption was the presence of babies in the groups, who were being cared for by the participants. In spite of these "disruptions", the facilitator noted that babies were part of the normal daily routine of participants, so their presence had limited impact on group discussions. Another possible limitation was that data was not collected on 'phone sharing', which is a common practice in poor households; nor on network coverage; the ability to charge a battery; phone specifications; airtime challenges; or the functionality of the

phone itself. Such data will need to be verified by a survey prior to implementing any communication technology strategy.

## Conclusion

This study found that participants face challenges related to caring for adolescents with mental health issues, and are interested in using communication technology to address these challenges. Information dissemination methods, via a mobile phone and publicly accessible computers, were preferred modes of information delivery.

Participants in this study revealed the challenges they faced when caring for adolescents with mental health issues, specifically psychosocial challenges, lack of social resources, and informational challenges. The group discussions and the visual presentations reflected these challenges. In this milieu, the researcher ascertained their inclination towards a communication technology intervention aimed at supporting caregivers through information. It was easier for participants to demonstrate challenges visually than it was to demonstrate informational needs.

The study found that participants were willing to use communication technologies for obtaining information, and this finding contributes to the importance of the research. Further research should involve a study of the feasibility and implementation of communication technology in a rural community setting. Furthermore, there is a need to examine the mental health issues faced by adolescents, and their relational experiences with their primary caregivers. Lastly, future work is required to explore the full potential of communication technology in South Africa for improving the health of adolescents with mental health issues, as well as of their caregivers.

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## CHAPTER 5: CAREGIVERS OF ADOLESCENTS WITH MENTAL HEALTH ISSUES USING COMMUNICATION TECHNOLOGY: A SYSTEMATIC REVIEW

### 5.1 INTRODUCTION

This chapter will present an article of a systematic review on the best evidence available on caregivers of adolescents with mental health issues using communication technology.

### 5.2 MANUSCRIPT DETAILS

Title	Caregivers of adolescents with mental health issues using communication technology: a systematic review
Authors	Ronelle Jansen and Marianne Reid
Journal	<i>JMIR mHealth and uHealth</i>
Journal details	Open access Peer-reviewed journal Listed as an accredited journal by the Department of Higher Education and Training (South Africa) Impact factor 4.301 (2019 Journal metrics) <a href="https://mhealth.jmir.org/">https://mhealth.jmir.org/</a>
Status	Accepted for publication
Author guidelines	<a href="https://www.jmir.org/content/author-instructions">https://www.jmir.org/content/author-instructions</a>

### 5.3 ASSOCIATED ADDENDA

The associated addenda listed here refer to the senior researchers' references (Addendum F) and the data extraction table (Addendum G) used during the critical appraisal process.

## Review

# Communication Technology Use by Caregivers of Adolescents With Mental Health Issues: Systematic Review

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## Abstract

**Background:** Caregivers of adolescents with mental health issues experience challenges that may result in the caregivers having a variety of unmet needs. There is a growing need to support these caregivers. Effective support to strengthen positive caregiving behavior in caregivers may address their challenges. Communication technologies offer novel opportunities to assist these caregivers and may contribute to strengthening caregiver behavior. However, little is known about the use of communication technologies among caregivers of adolescents with mental health issues.

**Objective:** The study aimed to answer the question: “What is the best evidence available to strengthen positive behavior of caregivers of adolescents with mental health issues using communication technology?”

**Methods:** A systematic review of articles published between January 2007 and August 2018 was conducted. Searches included articles of multiple study designs from EBSCO Host and Scopus platforms with prespecified eligibility criteria. Methodological quality was evaluated using the applicable Critical Appraisal Skills Programme and Joanna Briggs Institute assessment tools.

**Results:** The search yielded 1746 articles. Altogether, 5 articles met the eligibility criteria and were included in the review for data synthesis. Data analysis and synthesis identified three thematic conclusions reflecting the types of communication technologies used, caregivers as the target population, and strengthening of positive behavior through determinants of the Integrated Model of Behavior Prediction.

**Conclusions:** The review reported the usefulness of communication technology by caregivers. Caregivers also demonstrated improvement in self-efficacy, knowledge, parent-child communication, and parental skills reflecting positive behavior. Although the use of communication technology is expanding as a supportive intervention to address caregivers’ needs, the evidence for usefulness among caregivers of adolescents with mental health issues is still scarce. More research and information related to preferred methods of communication delivery among caregivers of adolescents is still needed.

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**KEYWORDS**

caregiver; communication technology; adolescent; mental health issues; systematic review; self-efficacy; knowledge; parental skills; IMBP

## Introduction

**Background**

“Nothing about me, without me” [1]

The caregiver landscape can be successfully supported through tailored solutions by acknowledging their unique challenges. Caregivers are largely invisible and are mostly underappreciated resources in community health services [2,3]. Caregivers are vital partners who contribute to health care provisioning in communities. They contribute to alleviating resource

deficiencies and assist with task sharing in the health sector, despite not formally being part of the health sector [4-6]. Regardless of this important contribution to health care delivery, caregivers receive minimal support from governments [7,8]. Globally, caregivers share a myriad of ongoing challenges and obstacles that are burdensome [2,9], often leading to unmet physical, psychological, and financial needs [10,11].

Caregivers' own needs are mostly neglected because there is usually more attention focused on the care recipient or the family's needs [12]. It is thus vital to identify the unmet needs of the caregiver independently from those of the care recipient [9,13]. Unmet needs of caregivers merit more recognition and understanding in order to employ effective support to their prioritized needs [14]. Interventions for caregivers may be beneficial to address needs such as skills training, support, education, and access to resources [15,16].

Fortunately, there is greater awareness of mediating interventions to support caregivers who are providing care for relatives with a chronic illness or disability [17]. Various interventions have been geared toward caregivers of persons presenting with dementia [14,18,19], cancer [20,21], HIV [22,23], chronic diseases [24-26], maternal and child health [27,28], and long-term conditions in children [29,30]. Various authors [31,32] claim that there is limited research available that focuses on families caring for adolescents with mental health needs, while Cardamone-Breen et al [33] stated there is a scarcity of parental interventions to prevent them from internalizing the mental health issues of adolescents. Parent- and family-focused interventions for child and adolescent mental health care are poorly represented in research [34-36]. Authors do not use similar terminology when referring to mental health issues, problems, illnesses, or conditions. This review will refer to *mental health issues* as a broad term for mental, emotional, and behavioral problems or disorders focusing on depression, anxiety, and substance use. Depression, anxiety, and substance use disorders are more common among adolescents [37-39].

Armoiry et al [40] reported equivocal findings regarding the use of communication technologies among families of young people with long-term conditions. Rodríguez-Meirinhos et al [31] also highlighted caregivers' need for education and information in preparation for caring for an adolescent with a mental illness. These authors [31] also established the necessity for dependable interventions to support families and community services to empower this group of caregivers.

Evidence-based supportive interventions that are flexible and developed according to the needs of caregivers may reduce caregiver burden and improve mental health caregiving [9]. Kuhn and Laird [41] stated that a combination of supportive interventions would be more useful for a diverse population, allowing tailored communication. Understanding caregivers' cultural context is important to develop a tailored intervention congruent to their specific needs [6,9,42]. Moreover, caregiver interventions should be sustainable [43], easily accessible [44], available [9], culturally, ethnically, and linguistically tailored [45], and caregiver-focused [46].

Literature suggests that communication technologies are arising as an acceptable intervention to assist caregivers of children

and young people in the management of conditions [40]. Communication technologies terminology is labeled interchangeably in the literature but refers to computers, the internet, electronic health (eHealth), and mobile health (mHealth), including networks and media services to transmit information [47-50]. This taxonomy of communication technologies is often used simultaneously in the research of interventions reporting on various outcomes [51]. Combined communication technology interventions often result in effective health outcomes and are feasible substitutes for traditional health promotion approaches such as printed material [52,53]. Vergunst [54] also recommended that creative interventions need to be established for caregivers in resource-poor settings such as rural areas to bridge gaps in mental health service delivery for the individual, the family, and the community. Although communication technology interventions are potentially valuable to support caregivers of children with mental and behavioral problems [55], limited data are available even though it is a major public health concern [56]. The emergence of communication technologies to deliver training for caregivers is increasing and show promise in real-world setting [57].

Evidently, the usefulness of communication technology interventions for caregivers of adolescents with mental health issues differs. DeHoff et al [58] found that parents of children with special needs got support through an online social platform to accept and manage the child's condition. Another study disclosed that parents of youth with mental health problems seem to be positive about the use of computer-based therapies [59]. A web-based health promotion program utilized by adolescent girls and their mothers for drug use, among other conditions, resulted in positive health behavior changes [60]. The study by Russell et al [61] indicated a high satisfaction among parents of children with behavior problems when engaging in a computer-based education program.

The novelty of communication technologies in the management of psychiatric and mental health illnesses may be valuable to investigate [62]. According to Casale et al [63] and Robila [64], there is a need to support parents through interventions that provide resources to improve parenting, particularly in reducing adolescent behavioral and emotional problems. It would appear that communication technologies are beneficial in supporting caregivers in improving their skills, abilities, self-efficacy, and knowledge [65,66]. A review of caregivers caring for adolescents with developmental disabilities similarly highlighted the effect of tailored interventions to augment caregivers' self-efficacy, self-esteem, positive coping skills, and supportive social networks [67].

### Theoretical Framework

The Integrative Model of Behavior Prediction (IMBP) endorses determinants such as attitudes, norms, and self-efficacy, by predicting behavior. Consequently, these determinants are based on underlying beliefs that, in turn, influence the intention to perform a specific behavior. Behavior may be challenged due to a lack of skills or environmental constraints [68,69].

The IMBP guided this review in clarifying caregivers' behavioral intention for utilizing communication technologies by determining their belief, attitude, norms, self-efficacy, skills,

environment, and intention. Behavioral intention can be predicted if the populations' beliefs, attitudes, norms, self-efficacy, skills, and environment are known [68,70,71]. To our knowledge, however, there have been no systematic efforts to synthesize evidence on the usefulness of communication technologies to strengthen positive behavior in caregivers of adolescents with mental health issues. Any positive response to a determinant was regarded as strengthening [71,72] of caregivers' behavior toward the adolescent.

The authors conducted a systematic review to collect and synthesize all evidence fitting the prespecified eligibility criteria. The authors sought to answer the following question based on the PICO format [73] (see Table 1 for the application of the PICO format): "What is the best evidence available to strengthen positive behavior of caregivers of adolescents with mental health issues using communication technology?" This paper provides a critical review and synthesis of the best available evidence about the use of communication technologies by caregivers of adolescents with mental health issues.

**Table 1.** Application of the PICO format.

PICO	Application
Population	Caregivers of adolescents with mental health issues (Caregivers namely families, parents, sibling, carer, etc)
Intervention	Communication technology
Comparison	Routine communication technology
Outcome	IMBP <sup>a</sup> determinants (beliefs, attitude, norms, self-efficacy, skills, environment, and intention)

<sup>a</sup>IMBP: Integrated Model of Behavior Prediction.

## Methods

### Design

The authors undertook a systematic review that included multiple study designs [73-75]. This systematic review has been registered in PROSPERO (CRD42018094680) and was conducted according to PRISMA guidelines.

### Search Strategy

A senior research librarian conducted a systematic search on electronic databases that covered articles published from January 1, 2007 to August 2, 2018. Databases from the EBSCO Host platform (PsycINFO, Academic Search Ultimate, MEDLINE with Full Text, Health Source: Nursing/Academic Edition, SocINDEX with Full Text, CINAHL with Full Text, ERIC, CAB Abstracts, MasterFILE Premier, Africa-Wide Information,

PsycARTICLES, OpenDissertations, Communication & Mass Media Complete, Business Source Ultimate, SPORTDiscus with Full Text, Health Source - Consumer Edition, Humanities Source, EconLit with Full Text, GreenFILE) and the Scopus database were included. No language or study design restrictions were applied. Search strings determined by the authors in collaboration with the research librarian were used to retrieve articles from the abovementioned databases. It was decided to make use of free text, as the search would be conducted on multiple databases, of which only MEDLINE and CINAHL utilize controlled vocabulary (MeSH and CINAHL subject headings respectively). Before conducting the search, a concept analysis was done to identify synonyms to be used in the free-text search (see Table 2 for a combination of the search string using Boolean operators). The first author (RJ) also searched the reference lists of retrieved articles. Dissertations and book chapters formed part of the retrieved articles.

**Table 2.** Search strings used.

Search strings
caregiver* OR "care giver*" OR family* OR families* OR parent* OR mother* OR father* OR sibling* OR carer OR carers OR "lay worker*" OR "next of kin" AND
"mental* health*" OR "mental* ill*" OR "mental* disorder*" OR "mental* diseas*" OR depress* OR anxiet* OR substance AND
teen* OR adoles* OR juvenile* OR youth* AND
belief* OR conviction* OR faith OR trust* OR norm OR norms OR custom* OR attitude* OR outlook* OR approach* OR Self-efficac* OR ability* OR Skill OR skills OR expertis* OR able OR abilit* OR talent* OR proficien* OR knowhow OR capabilit* OR knack OR competen* OR Intent* OR determination* OR planning OR resolve OR decide* OR decision* OR choose OR select* OR choice* AND
mobile* OR cell* OR smart OR sms OR "short message service*" OR text* OR device* OR mhealth* OR m-health* OR ehealth* OR e-health* OR "instant messag*" OR app OR apps OR phone* OR smartphone* OR "electronic device*" OR "portable device*" OR "phone intervention*" OR "telephon* intervention*" OR online*) not ("stem cell*" OR "sickle cell*" OR "assist" device*" AND
mobile* OR cell* OR smart OR sms OR "short message service*" OR text* OR device* OR mhealth* OR m-health* OR ehealth* OR e-health* OR "instant messag*" OR app OR apps OR phone* OR smartphone* OR "electronic device*" OR "portable device*" OR "phone intervention*" OR "telephon* intervention*" OR online* OR caregiver* OR "care giver*" OR family* OR families* OR parent* OR mother* OR father* OR sibling* OR carer OR carers OR "lay worker*"

### Eligibility Criteria

Articles were eligible for inclusion if they (1) focused on caregivers such as families, parents, siblings, or relatives of adolescents with mental health issues (concentrating on depression, anxiety, and substance use disorders) as the target population, (2) reported on communication technology usage, and (3) described caregiver determinants according to the IMBP. Articles were excluded if they did not meet the inclusion criteria or (1) if they focused only on adolescents as the target population, (2) if they reported on non-communication technology interventions, and (3) if the focus was on mental health-related therapies or traditional communication interventions.

### Selection Procedure

The first author (RJ) filtered all titles and abstracts obtained from the search against the review question and eligibility criteria. The second author (MR) verified articles for compliance with eligibility criteria. A large number of articles were excluded, and duplicates were removed. Full-texts for the remaining articles were obtained from the librarian. These

full-text articles were independently screened for eligibility by both authors, and any discordances were resolved through discussion. Additionally, references of selected articles were screened further for relevant studies.

### Quality Appraisal

The first author (RJ), together with two senior researchers, rigorously evaluated the quality of the selected articles according to the Critical Appraisal Skills Programme [76] and Joanna Briggs Institute assessment tools applicable to each study design [77]. All tools evaluated the appropriateness of methods used, clarity of focus, the recruitment process, the accuracy of measures used, data collection, presentation and analysis, clarity in the statement of the findings, and appropriateness of context. If more than two aspects were not addressed in the articles, it was excluded. This was depicted as either Level 1\* (full marks obtained) or Level 1 (-1 mark) in Table 3. Table 3 includes a hierarchy classification system in terms of research design, according to the American Dietetic Association [78,79]. This critical appraisal of the full-text articles determined the selection and inclusion of articles in this systematic review.

Table 3. Summary of included articles' study designs.

Extracted data	Reference				
	Deitz et al [80]	Cardamone-Breen et al [33]	Choi et al [81]	Molleda et al [82]	Estrada et al [83]
Design	Randomized control trial	Randomized control trial	Quasi-experimental	Qualitative, descriptive	Qualitative interviews
<b>Grading</b>					
Level	1	1	1*	1	1
Hierarchy	A	A	C	D	D
<b>Communication technology</b>					
Type	Web-based	Web-based	Web-based	Internet-based, eHealth	Internet-based, eHealth, tablets
Reminders	Multiple—not specified	—	Phone calls, text messages, and emails	—	Phone or text messages
Financial support	National Institute on Mental Health	National Health and Medical Research Council	Korean government	—	Centers for Disease Control and Prevention (grant)
Recruitment	—	Online networks, social media, computer, online parent portals, and email communication	Via online communities	Emails	Online
Follow-up		Phone calls, text messages, and emails			
<b>Targeted</b>					
Caregivers	Parents, n=99	Parent/caregiver, n=349	Parents, n=114	Parents, n=6	Parents, n=29
Youth/ adolescents	Mental health problems or issues	With depression and anxiety disorders	Mental health problems or issues (common mental health problems (ie, bullying, depression, internet addiction, and suicide)	With drug use and risky sex behavior	With drug use and sexually risky behavior
Setting	Workplace of parents: ISA Group in Alexandria in the US	Secondary schools in Australia	Two elementary schools and four middle schools from four cities in Korea	Pediatric mobile clinic in Miami-Dade County and another clinic located on the university medical campus (University of Miami Miller School of Medicine)	Multiple middle schools relatively close to where the families lived and at the University of Miami offices.

### Data Extraction, Analysis, and Synthesis

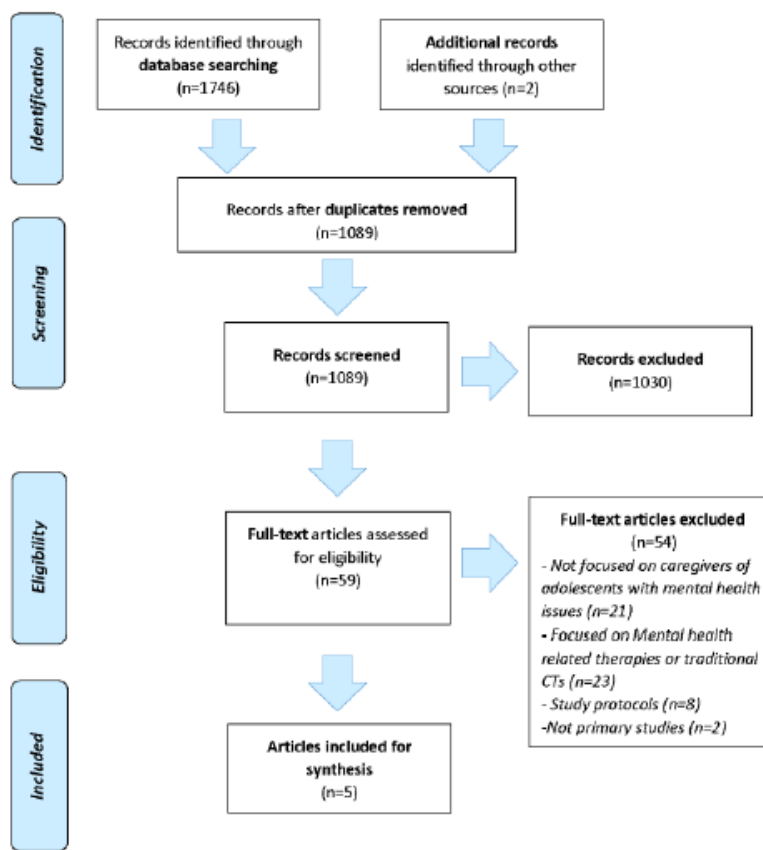
The authors extracted specific data from the selected articles in a tabular format to record the study characteristics, types, and delivery method of communication technologies and the strengthening of positive behavior according to IMBP determinants. A meta-analysis was not feasible due to the heterogeneity of the included articles. A thematic data analysis [84-86] took place and both authors discussed the themes to refine the data according to the review question. Subsequently, the data were organized into relevant thematic conclusions addressing the research question based on the PICO elements. After that, the results were synthesized across all articles.

### Results

#### Search Results and Selection of Articles

The search identified 1746 electronic records of possible interest. Two additional articles were added, one through contacting an author and another through reference list checking. After electronic and manual removal of duplicates, 1089 records remained. Further screening for eligibility of identified records resulted in the retrieval of 59 full-text articles that were potentially relevant for analysis. The authors then conducted a comprehensive review of these full-text articles and included articles that specifically focused on communication technologies used by caregivers of adolescents with mental health issues. A total of 5 articles met all the eligibility criteria. Figure 1 presents the PRISMA flow diagram of the study, and Table 3 presents a summary of the included articles' study design evaluations.

Figure 1. PRISMA flow diagram.



### Characteristics of Included Articles

The final articles included in this systematic review consisted of multiple designs. There were 2 randomized controlled trials [33,80], 1 quasi-experimental study [81], and 2 qualitative studies [82,83]. In all 5 articles, the caregivers had been exposed to communication technologies in caring for adolescents with mental health issues. Of the 5 studies, 3 studies were performed in the United States [80,82,83], 1 was performed in Australia [33], and 1 was performed in Korea [81]. Articles varied in

methodology, intervention, outcomes, measurement scales, and findings. Not all of the articles complied with all of the identified IMBP determinants leading to positive behavior. Table 4 presents a summary of the results reported by the 5 articles.

Results from the 5 articles were synthesized and thematically analyzed to formulate conclusions. The thematic conclusions are discussed according to the types of communication technologies used, caregivers as the target population, and strengthening of positive behavior through IMBP determinants.

Table 4. Summary of results reported by the 5 articles.

Reference	Strengthening positive behavior according to determinants within IMBP <sup>a</sup>
Deitz et al [80]	Total knowledge score: significantly greater for the experimental group than the control group ( $t=-7.96, P<.001$ ) Knowledge of treatment: statistically significant ( $t=-2.92, P=.006$ ) A significant difference was found between experimental and control groups on self-efficacy in handling mental health issues in their children ( $F=12.73, P=.001$ ). Significant paired $t$ test analysis of increases in self-efficacy from pretest to posttest among the individuals receiving the intervention was found ( $t=-3.20, P=.003$ ). No significant differences between groups on the measures of family communication, adaptability, cohesion, and attitudes toward mental health issues were found.
Cardamone-Breen et al [33]	Chi-square analyses of the postintervention (1-month) assessment revealed a significant difference in attempts to change parenting ( $n=307, \chi^2=19.65, P<.001$ ), with significantly more intervention group parents reporting making some changes to their parenting. The majority of parents (93.6%) reported they were somewhat or very satisfied with the feedback received, and 95.1% reported the feedback as either somewhat, very, or extremely useful. Most parents (90.2%) reported they were somewhat or very likely to change their parenting based on the feedback provided. Conclusion: accessible, low-cost preventive approach
Choi et al [81]	Participants in the intervention, compared to those in the control group, demonstrated preliminary evidence of improved parental knowledge. The effect size of parental knowledge was large ( $d=0.60$ ; 95% CI 0.21-0.99). Parents in the intervention group showed increased parental self-efficacy, parent-child communication, and satisfaction with parent-child relationships, and decreased parent-child conflict. Parents reported accessibility and convenience to complete the intervention.
Molleda et al [82]	Effective parent-adolescent communication skills. Parents' positive experience with flexibility, accessibility, and convenience in delivery of eHealth. Parents also reported the ability to apply the lessons learned from eHealth <i>Familias Unidas</i> to their daily lives.
Estrada et al [83]	It was feasible to recruit, engage, and retain Hispanic families into an eHealth intervention and deliver it electronically. Positive feedback was provided by the parents regarding eHealth. Parents stated there were multiple lessons learned from engaging in eHealth <i>Familias Unidas</i> : effective parent-adolescent communication and active parental attention and involvement in an adolescent's life. Culturally appropriate online content allowed parents to access sessions at their convenience and minimized costs for researchers and participants alike

<sup>a</sup>IMBP: Integrated Model of Behavior Prediction.

### Types of Communication Technologies Used

All the studies implemented web-based interventions [33,80-83]. Content employed via the communication technologies and delivery thereof varied considerably. The web-based program by Deitz et al [80] consisted of 4 multimedia modules that provided information regarding symptoms and treatment options for depression and anxiety, building parental skills, and additional resources with information about mental health issues. Parental skills included communication, relationships, and healthy lifestyles. Estrada et al [83] and Molleda et al [82] adapted an evidence-based intervention, *Familias Unidas*, into a web-based intervention consisting of 8 e-parent group sessions of video recordings and 4 online family sessions (parent-adolescent) with a facilitator. Choi et al [81] reported on a 4-week web-based intervention (Stepping-stone) containing educational sessions, media files, verbal feedback, weekly assignments, and practice sessions regarding bullying, depression, suicide, and communication skills. Cardamone-Breen et al [33] adapted a single-session web-based component of the Partners in Parenting intervention. This intervention provided personalized feedback and psychoeducation concerning guidelines on adolescent depression

and anxiety after the parents completed an online survey to assess parenting practices.

### Target Population

The study populations in the included articles predominantly comprised caregivers as parents or family members. Deitz et al [80] used parents or caregivers of youth between the ages 5 and 21, while Molleda et al [82] included clinic personnel, facilitators (ie, physicians, nurse practitioners, administrators, and mental health workers), and parents or primary caregivers of Hispanic adolescents (age range: 12 to 16 years) [82]. Estrada et al [83] also included Hispanic families with parents and adolescents between the ages of 12 and 16 [83]. The study by Choi et al [81] encompassed parents who had at least one child aged 11 to 16 years. Cardamone-Breen et al [33] used a community sample of parents, together with adolescents aged 12 to 15 years old. The most common problems among adolescents were mental health or behavioral issues [80,81], depression and anxiety disorders [33,81], bullying [81], suicide [81], and substance use [82,83]. The majority of participants in the studies were female, recruited from various urban settings, and educated.

### IMBP and Other Determinants

Outcomes focusing on the IMBP determinants in the current review were about self-efficacy and skills such as parent-child communication: 2 studies [80,81] measured the effect of the intervention on caregiver self-efficacy that improved after the intervention; 3 studies [81-83] also demonstrated the effectiveness of communication skills between caregiver and adolescent, and 1 randomized controlled trial [80] measured no significant differences between study groups in family communication skills. Of the 5 studies, Cardamone-Breen et al's study [33] showed promising changes in parenting skills and behavior, and another study [80], a randomized control trial, reported outcomes regarding parental attitudes demonstrating no significant differences between the two study groups.

Another observation was that effective parental skills resulted in satisfactory parent-child relationships as well as a decline in parent-child conflict [81]. Caregivers similarly appreciated the feedback they received regarding their parental skills after using the intervention [33] and lessons learned to implement in their daily lives [82,83].

We identified 2 studies [80,81] that measured the effect of communication technologies use on caregivers' knowledge showing an improvement. Additionally, Estrada et al [83] found that parents were more involved and attentive in the life of adolescents after engaging with the eHealth intervention. In turn, participants in Estrada et al's study [83] gave positive feedback regarding the use of the eHealth intervention while Molleda et al [82] found that parents experienced the eHealth delivery as positive.

## Discussion

### Principal Findings

The review results show the potential value of communication technologies to strengthen caregivers' behavior when caring for an adolescent with mental health issues. Overall, the results yielded evidence of the usefulness of communication technologies by caregivers. Moreover, the results contributed to the limited literature on communication technology interventions for caregivers caring for the adolescent with mental health issues.

As shown by this study, the results were mostly positive, which may raise questions about selection bias. Aligned to the review question, we were interested in determinants showing improved outcomes among caregivers' when using communication technologies. It becomes particularly imperative to recognize users' preferences and acceptance of communication technologies in a health care setting. Identifying appropriate communication technologies to inform and support caregivers may be a challenge, but it is essential to understand their adoption thereof [87,88]. Information dissemination delivered through communication technologies is gradually replacing traditional approaches [89], but the implementation in health care [90] and among caregivers [14,91] is still lacking.

Communication technologies can distribute an unprecedented amount of information through technology such as electronic devices, system software, and information networks such as the

internet, which provides access to resources [92,93]. Moreover, Schneider's [94] systematic review reported that utilizing communication technologies to gather and stream information received the highest proportion of use. Multimedia approaches including internet and web-based programs are a means for providing informational support to caregivers; they also found that effective parent education through communication technologies can augment the mental well-being of children [95]. Our results are consistent with earlier reports in this field that suggest that web-based interventions are effective for caregivers managing mental health issues in adolescents [91,96,97].

A prevailing expectation of communication technologies is that it might improve knowledge acquisition regarding illnesses. However, applicable information should be according to the caregivers' specific needs [98]. Statistically significant differences were found related to parental outcomes of knowledge, attitudes, and skills in efficient web-based interventions [99]. Exploiting the internet for knowledge about chronic diseases, as noted by Mahmud et al [53], can assist individuals and communities in health promotion. In contrast, low-income parents were not confident in using the internet and could not distinguish between good- or bad-quality information [100]. Sweeney et al [59] concluded that parents of youth with mental health problems demonstrated poor knowledge regarding computer-based therapies but were positive about using it.

Communication technologies are now mature enough to enable learning and knowledge exchange among caregivers in health care [101]. This functionality is attributable to the fact that communication technologies are associated with boosting the health care landscape through information exchange and transformation among large populations [102]. Our review indicated some evidence that computer-based interventions among large groups of parents are less expensive. The financial implication is particularly relevant in the current global socioeconomic climate, especially in low-resource settings that should keep cost-effectiveness of communication technologies in mind [103] when serving vulnerable populations such as caregivers in deploying health care [104]. According to Sprague et al [105], the world still experiences barriers to internet adoption despite high technology penetration because of disproportionately rural populations, low-income, illiteracy, elderly users, and female users. Therefore, it is vital to explore the best evidence available related to communication technologies barriers such as delivery methods, cost-effectiveness, caregiver characteristics, and outcomes, which will predict adoption thereof.

None of the included studies measured text messaging, phone calls, mobile apps, or social networking as a favored network delivery; however, included studies mentioned the use of communication technologies to recruit participants and send reminders. Domek et al [106] and Anderson-Lewis et al [107] suggest that text message interventions may be useful in rural families and have the potential to disseminate public health information. Mobile apps show some promise in serving families of youth with mental health issues in resource-constraint settings [108]. Breitenstein et al [109] also determined that digital delivery, such as mobile apps, might theoretically be

cost-effective, sustainable, and reach large numbers for parent training. Furthermore, some studies [110,111] have shown that social media effectively supports and informs caregivers through shared participation. Catalano et al [112] identified that parental social support and interacting improved caregiver well-being.

Collective participation is valuable, but researchers should be mindful of caregivers' individuality when exploring the usage of communication technologies. It is important to conceptualize the characteristics of caregivers in the context of communication technologies acceptance [113-115]. Caregivers of adolescents are typically a parent or family member who assumes a central role in caregiving. Transition into the caregiver role can be different for each caregiver. Recognizing the individual needs of each caregiver is crucial when investigating the usability of communication technology interventions [9,116], especially in caregivers of children or adolescents with mental health issues [67,117,118].

Caregivers' adoption of tailored web-based interventions focusing on their needs may improve their resourcefulness and mobilize effective caregiving [119,120]. Tailored communication technologies was highlighted in this review, indicating contextual relevance related to the usage of communication technologies. Besides, this review also highlighted common elements depicting their approval of utilizing communication technologies, such as the accessibility, cost-effectiveness, convenience, and flexibility thereof. Generally, study participants gave positive feedback related to communication technologies use. Modifying communication technology interventions to match caregivers' preferences might lead to favorable changes in parenting practices and satisfaction in intervention utility [121]. Overall, the findings demonstrated the acceptability of communication technologies by caregivers, and the use of communication technologies was associated with improved caregiver and mental health outcomes among adolescents.

Some studies in this review identified diverse interventions that facilitated the strengthening of caregivers' behavior, such as improved self-efficacy, enhanced knowledge, and better parent-child communication skills and practices. These findings complement those of other studies in that online tools have proved to be successful in improving caregivers' knowledge, skills, coping [122,123], and self-efficacy [120,124]. Nieuwboer et al [99] summarized that the internet supplies information, support and advice to parents with different needs that encourage changes in their parental abilities. Furthermore, technology provides access to others for building support and knowledge through positive engagement [125]. Reportedly, the potential impact of communication technologies on caregivers' well-being is ubiquitous and may guide their behavior toward the care recipient [126].

Caregivers who feel that they can perform behavior effectively will continue to repeat that specific behavior. This performance is based on knowledge, skills, and self-efficacy. A repetition of the behavior will occur if it is associated with a positive feeling and a sense of confidence; the accomplishment of the behavior,

reflects self-efficacy and competency in performing the task [127,128]. People hold specific beliefs about behavior and intentionally perform according to that belief. From the IMBP, people who have the necessary skills will perform more satisfactorily, which will lead to favorable outcomes [129]. Hall and Bierman [130] reported improvement in parental knowledge and attitude through technology-based interventions. Of course, targeted interventions strengthening parental knowledge, self-efficacy, and skills may lead to improved child mental health outcomes [100] and positive parental outcomes [9].

Thus, it is legitimate to say that a communication technologies-based intervention has great potential to be used by caregivers to reinforce positive behavior when caring for an adolescent with mental health issues. Communication technologies also represent possibilities to provide support to caregivers by addressing their individual needs which could be highly convoluted. This review shows a need for further research in the area of supporting caregivers of adolescents with mental health issues.

### Strengths

The authors conducted a comprehensive review following a stepwise methodological process for a systematic review. We included multiple study designs to understand how communication technologies may strengthen caregivers' behavior and improve caregiver outcomes. We used standardized checklists to appraise selected articles critically. The results provided knowledge related to the use of communication technologies among caregivers of adolescents with mental health issues.

### Limitations

We might have missed potentially relevant articles, although explicit inclusion and exclusion criteria were set up. The first author initially screened titles and abstracts independently for applicability while some were verified by the second author for quality control purposes. This review was limited to articles describing caregiver outcomes according to the IMBP determinants, and this restriction may have eliminated meaningful information from other communication technology advantages.

### Conclusions

The review results indicate that using communication technology is useful to strengthen caregivers' behavior by providing information and resources. Additionally, a better understanding of caregivers' attitudes and environmental constraints toward communication technologies may inform optimal usefulness thereof. Evidence for caregivers of adolescents with mental health issues using communication technologies is not readily available in the literature. There was limited empirical research outlining the methods of communication delivery, and it is worth exploring this in future research. Besides, future research should focus on the development of more innovative communication technology interventions for caregivers in different contexts and scaling up of efforts to implement them for improved mental health care among adolescents.

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### Authors' Contributions

RJ and MR conceptualized and designed the study. RJ and MR developed search strategies. RJ and MR conducted data extraction, analysis, and synthesis. MR contributed to the revision and approval of the manuscript.

### Conflicts of Interest

None declared.

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## Abbreviations

**eHealth:** electronic health

**IMBP:** Integrated Model of Behavior Prediction

**mHealth:** mobile health

**PICO:** population, intervention, comparison intervention, outcome

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**CHAPTER 6:  
A FRAMEWORK FOR DEVELOPING AN MHEALTH INITIATIVE TO SUPPORT  
RURAL CAREGIVERS OF ADOLESCENTS WITH MENTAL HEALTH ISSUES**

**6.1 INTRODUCTION**

This chapter will present a manuscript that describes the framework developed for an mHealth initiative to support rural caregivers of adolescents with mental health issues.

**6.2 MANUSCRIPT DETAILS**

Title	A framework for developing an mHealth initiative to support rural caregivers of adolescents with mental health issues
Authors	Ronelle Jansen and Marianne Reid
Journal	<i>Mass Communication and Society</i> (Routledge Journals, Taylor & Francis Ltd)
Journal details	International Open access Peer-reviewed journal Listed as an accredited journal by the Department of Higher Education and Training (South Africa) Impact factor 1.792 (2019 Journal metrics)
Status	Under review
Author guidelines	<a href="https://www.tandfonline.com/action/authorSubmission?show=instructions&amp;journalCode=hmcs20">https://www.tandfonline.com/action/authorSubmission?show=instructions&amp;journalCode=hmcs20</a>

**6.3 ASSOCIATED ADDENDA**

Addenda associated with Phase 3 are the information leaflets and consent forms (Addendum H).

## **A framework for developing an mHealth initiative to support rural caregivers of adolescents with mental health issues**

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### **Abstract**

Caregivers of adolescents with mental health issues shoulder a heavy caregiving burden while also facing their own unmet needs. The various unmet needs of rural caregivers necessitate supporting initiatives, and evolving mHealth initiatives may provide opportunities to support caregivers. Frameworks to inform intervention development for caregivers are lacking. This study aimed to develop a framework for an mHealth initiative to support rural caregivers of adolescents with mental health issues. A multiple method design guided framework development through a three-phase approach. Phase 1 employed a visual-based narrative inquiry to investigate interest in communication technology by rural caregivers of adolescents with mental health issues. Phase 2 included a systematic review on caregivers of adolescents with mental health issues using communication technology. Results from Phases 1 and 2 were triangulated to develop a draft framework based on the theory-of-change logic model. The draft framework was validated in collaboration with expert stakeholders involved in adolescent mental healthcare during a workshop in Phase 3. Contributions made by the expert stakeholders are outlined in the final framework. This article describes a framework for an mHealth initiative for rural caregivers of adolescents with mental health issues, constructed from evidence-based data.

### **Keywords:**

Rural caregivers, adolescents, expert stakeholders, validation workshop, theory of change, framework

## **Background**

*'Quietly endure, silently suffer, and patiently wait.'*

*Martin Luther King, Jr.<sup>1</sup>*

Globally, caregivers suffer many burdens, and caregiving responsibilities at home influence their well-being (Bingham, 2017; Stacey et al., 2016). Traditionally, home care is seen as a social obligation, which is accepted by many women across the world (Berry & Malek, 2017; Larkin et al., 2019; Ruiz & Nicolás, 2018). Care recipients are individuals with various acute or long-term conditions, age-related issues, or physical and mental health issues or disabilities, and include children/adolescents living at home (Larkin et al., 2019; National Research Council, 2010; Stacey et al., 2016). In most settings, parents, grandparents, and close family members act as caregivers and are central in caring for adolescents (Berry & Malek, 2017; Gérain & Zech, 2018, 2019). Caregivers are well positioned to recognise any changes in adolescents' behaviour (National Research Council, 2010; Toska et al., 2019) caused by challenging transitions that impact the adolescent and the family's daily functioning (Das-Munshi et al., 2016; Dogra et al., 2002; Patton et al., 2016).

Caregivers' caregiving practices concerning adolescents are challenged by the need to distinguish between normal developmental behaviour, and presentation of mental health issues (Das-Munshi et al., 2016; Paruk & Karim, 2016). Caring for individuals with mental health issues presents caregivers with difficulties (Chadda, 2014; Chang et al., 2016; Van Pletzen & MacGregor, 2013) while caring for adolescents with mental health issues often makes caregivers feel incompetent regarding their caring responsibilities (Campelo et al., 2014; World Health Organization, 2017). Caregivers are fundamental for adolescents' mental

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<sup>1</sup> <https://www.quotetab.com/quote/by-martin-luther-king-jr/quietly-endure-silently-suffer-and-patiently-wait?source=struggle>

health, but frequently have little understanding about adolescent behaviour, thereby creating difficulties regarding coping, and managing behaviour (Campelo et al., 2014; Valverde et al., 2012; Veldman et al., 2015).

Accessibility barriers to mental healthcare services in rural areas shift the responsibility to the adolescent's caregiver (Siceloff et al., 2017). Caregivers in rural communities experience challenges due to human and mental health resource deficiencies (Denby & Bowmer, 2013; Gamm et al., 2003) and experience isolation (Henning-Smith & Lahr, 2018). Rural caregivers have been found to lack education regarding adolescent behaviour and mental health (Choate, 2015; Michael & Jameson, 2017), they lack exposure to health promotion strategies (Campelo et al., 2014), and often feel unsupported (Choate, 2015).

According to Chen et al. (2019), there is little caregiver support to address their needs, while the National Academies of Sciences, Engineering, and Medicine (2019) emphasise the importance of addressing rural caregivers' needs. Stavrou et al. (2017) state that providing support is expected to ease caregiver burden, whereas Bastawrous (2013) confirms that, if caregivers receive adequate support, they can overcome the difficulties they experience.

Unsupported caregivers may struggle with increased burdens (Mendenhall & Mount, 2011), which impacts their well-being and quality of life (Cheng et al., 2017; Talley et al., 2014).

Caregivers have to look after adolescents with mental health issues, as well as their own well-being, which means they have to carry a double burden (Schor, 2003; Stacey et al., 2016; Talley et al., 2014).

Rodríguez-Meirinhos et al. (2018) are of the opinion that initiatives that address caregivers' multiple needs may improve their well-being, ability to cope, and quality of life. Therefore, Brown and Brown (2014) believe that recognising the needs of caregivers may optimise initiatives that target their specific challenges. Effective caregiver support initiatives could

also improve the care recipient's outcomes (Chen et al., 2019; Feinberg, 2014; Feinberg & Houser, 2012). Initiatives to improve the outcomes of the behaviour of both the caregiver and adolescent are beneficial to both parties. Lafferty et al. (2016) propose versatile initiatives that signify individual needs specific to each caregiver situation, because "one size does not fit all".

Information and communication technologies (ICTs) emerged as promising initiatives for meeting caregivers' needs. ICTs can provide support to anyone, anywhere, and anytime (Aceto et al., 2018; Negash et al., 2018) by supplying among others information (Mothobi & Gillwald, 2018; Newman et al., 2019), connections (Newman et al., 2019; Trilar et al., 2018), and education (Källander, 2010; Källander et al., 2013; Mothobi & Gillwald, 2018), and can aid in decision-making (Avgar et al., 2012; Källander et al., 2013). mHealth (mobile health) and eHealth (electronic health) are components of digital communication technologies for healthcare (digital health) (Istepanian et al., 2003; Källander et al., 2013; Mechael et al., 2010). mHealth is widely recognised as an accessible vehicle to deliver healthcare initiatives (Källander et al., 2013; McCarthy et al., 2018) through mobile devices, such as mobile phones (Delponte et al., 2015; Marin et al., 2017), and offers solutions through various functionalities, such as text messaging (SMS), multimedia messages (MMS), mobile applications, social media networks, and the Internet (Anderson-Lewis et al., 2018; Botha & Boo, 2016; Klasnja & Pratt, 2012; Payne et al., 2015).

mHealth technology has demonstrated effectiveness in developing countries, especially in rural areas that have limited resources due to staff shortages, too few clinics, and inaccessible healthcare information (Vital Wave Consulting, 2009). mHealth technology is rapidly emerging in healthcare settings, minimises the digital divide in resource-constrained areas (World Health Organization, 2018a, 2018b), and provides cost-effective caregiver support in

these areas, due to its promising abilities (Anderson-Lewis et al., 2018; Danis et al., 2010; Istepanian & Lacal, 2003; Klasnja & Pratt, 2012). Appealing mHealth attributes could facilitate efficient healthcare through communication, education, support, and information (Abroms et al., 2012; Goel et al., 2013), and could preserve caregivers' well-being (Frisbee, 2014; Talley et al., 2014) and coping skills (Aschbrenner et al., 2010).

Nascent mHealth initiatives contribute to support caregivers' in-home and community care (Davies & Lund, 2017; Gentles et al., 2010) during difficult times. Unique challenges facing caregivers necessitate tailored initiatives to support caregivers in suitable ways (Chi & Demiris, 2015; Tang et al., 2018), especially caregivers in rural areas (Chand et al., 2016; Laidlaw et al., 2017), who have particular support needs. Including caregivers intentionally in the development of initiatives may contribute to the success of initiatives (Wolff et al., 2016). Planning and developing caregiver mHealth initiatives should, similarly, engage relevant stakeholders (Aranda-Jan et al., 2014; L'Engle et al., 2017). Stakeholders of various healthcare settings can add value to the effectiveness and usefulness of mHealth initiatives (Franz-Vasdeki et al., 2015). Partnerships between relevant stakeholders and caregivers in developing mHealth initiatives could facilitate new means of support for rural caregivers, that could be potentially beneficial to both the creators (stakeholders) and the users (caregivers). Caregiver-focused initiatives that have been developed to transform caregiving practices (Bergström & Hanson, 2017; Yesufu-Udechuku et al., 2015) may improve behavioural outcomes in caregivers (Reichow et al., 2013). Initiatives for caregivers improving behavioural outcomes are unsuitable unless they are guided by a framework to define the programme activities that should be addressed by the mHealth initiative (Van Houtven et al., 2011).

Articulating a framework could be the starting point of initiatives (Funnell & Rogers, 2011), and could also ensure that feasibility is maximised (Yardley et al., 2015). Such a framework is needed to understand the detailed components of the initiative (Wilhide III et al., 2016) to determine caregiver outcomes. Daily caregiving should be strengthened by applicable initiatives that produce positive outcomes in caregiver behaviour. A clearly stated framework could foster desired results, such as behaviour change, including improving knowledge and attitudes, skills and intentions (Funnell & Rogers, 2011) of caregivers.

The integrated model of behaviour prediction (IMBP) explains and predicts behaviour changes, which signify the individual's intent to perform specific behaviour, influenced by attitudes, norms, and self-efficacy. Other factors that determine behaviour changes are lack of skills and environmental constraints (Admiraal et al., 2013; Fishbein & Yzer, 2003).

The researchers anticipated that mHealth initiatives would encourage rural caregivers to change their behaviour and achieve positive outcomes. As a theoretical model, the IMBP offers an understanding of the factors that affect behaviour change, which could be exposed by a theory-of-change framework.

Developing a framework to identify the components of the proposed initiative may contribute to more positive behaviour with possible behaviour change (Mayne, 2015). The researchers determined a need for a framework to guide the development of an mHealth initiative that attempts to support caregivers' caregiving behaviour. To create a suitable framework, the researchers drew on empirical evidence informing framework development. The framework discussed in this article focuses on an mHealth support initiative for rural caregivers of adolescents with mental health issues.

### ***Theoretical underpinning of the framework***

To develop the draft framework, the researchers drew on the theory-of-change logic model method (De Silva et al., 2015; W.K. Kellogg Foundation, 2004). A theory-of-change logic model consists of a series of components that conceptualise framework development, implementation, and evaluation, by explaining practically how, why and to what extent change can happen in a complex intervention (Mertens & Wilson, 2019; Serrat, 2017). A logic model displays a programme's theory of change (Serrat, 2017) by conceptualising programme planning through a graphic description of activities (Fernandez et al., 2019; Hernandez, 2000; W.K. Kellogg Foundation, 2004), by illustrating the interactions, causal links, and pathway connections (Harries et al., 2014) towards the proposed framework. Constructing a theory-of-change logic model occurs through a consultative process with relevant stakeholders (Breuer et al., 2016; De Silva et al., 2014; W.K. Kellogg Foundation, 2004), who map out the series of framework components (De Silva et al., 2015) to deliver a product (Vogel, 2012a; World Health Organization, 2016). Presenting a draft framework in an interactive workshop will yield discussion, and verify meaning, credibility, and ownership of the initiative addressed by the framework (Knowlton & Phillips, 2013; Nielsen et al., 2017). A workshop involving various stakeholders allows the sharing of information and knowledge, brainstorming, and discussion so that participants reach consensus about developing a contextual framework (Mason & Barnes, 2007; Mayne, 2015). The theory-of-change logic model is supported by the triangulation of evidence from various research designs (Vogel, 2012b; W.K. Kellogg Foundation, 2004) used to develop the framework.

### ***Methods***

A multiple method design guided the development of the mHealth framework through three phases. Three separate studies are depicted as phases that inform the development of the

mHealth framework for rural caregivers of adolescents with mental health issues. In Phase 1, the researchers employed a visual-based narrative inquiry. In Phase 2, the researchers conducted a systematic review, and Phase 3 consisted of a validation workshop.

### ***Research process***

The three-phase approach ensured a cumulative and iterative process for triangulating empirical data provided by rural caregivers (Phase 1), a systematic review (Phase 2), as well as data based on the knowledge of expert stakeholders during a validation workshop (Phase 3). The methodology for developing the framework will be described next.

### ***Phase 1: Visual-based narrative inquiry***

Empirical data were obtained through the Mmogo-method<sup>®</sup>, through which caregivers' interest in using communication technology was explored. The Mmogo-method<sup>®</sup> involves an indigenous focus group, which uses individual visual constructions as the baseline for group discussion. Three groups were held with rural caregivers (n=17) of adolescents with mental health issues in the Free State province of South Africa. A six-step thematic data analysis approach proposed by Clarke and Braun (2013) was followed for textual data, and visual analysis was conducted according to Roos and Redelinghuys' (2016) six steps. Meanings and contextual sensitivity of the data were verified through member checking during each group discussion.

The thematic analysis depicted four themes and relevant subthemes. Caregivers faced various challenges: They mentioned a need for psychosocial support and social resources, and that they faced informational challenges related to communication technology. Caregivers preferred using SMS and phone calls, and computers as supportive platforms, to access information (Jansen & Reid, 2020b).

### ***Phase 2: Systematic review***

The researchers undertook a systematic review of the best evidence of ways communication technology could strengthen positive behaviour of caregivers of adolescents with mental health issues. Of an initial 1 746 articles, five met the eligibility criteria and were included in the data synthesis. The applicable Critical Appraisal Skills Programme (CASP, 2014) and Joanna Briggs Institute assessment tools (Godfrey & Harrison, 2015) were used to evaluate the quality of the selected articles. Thematic data analysis was done to summarise the thematic conclusions.

The three thematic conclusions were that caregivers (particularly parents and family members), as the target population, experienced improved IMBP determinants (self-efficacy, knowledge, parent/child communication, parental skills), which reflects a positive effect on caregiving behaviour by using various types of communication technologies (SMS, emails, phone calls, online communication, social media) (Jansen & Reid, 2020a).

### ***Development of the draft framework***

The authors synthesised the results obtained from Phases 1 and 2 of the study to develop the draft framework for caregivers of adolescents with mental health issues. Triangulation of data culminated in conclusions that were used as foundation for the draft framework, which was presented during the validation workshop in Phase 3. The draft framework was structured according to the theory-of-change logic model.

### ***Phase 3: Validation of framework***

Nine stakeholders were purposively invited to participate in the one-day workshop to validate the draft framework. The stakeholders were experts in adolescent care and were in a position to influence mental health policy development. The group consisted of various DoH

representatives, such as the senior mental healthcare manager, professional nurse researcher, chief occupational therapist, assistant director physiotherapist, social worker, DoH head psychiatrist, DoH network administrator and, from the academia; the community-based coordinator, as well as a religious youth minister. All these stakeholders provided written informed consent.

Data from Phases 1 and 2 were discussed with expert stakeholders, and the layout of the theory-of-change logic model was explained to them. Author 2 facilitated validation of the draft framework through a forward and backward mapping process, which enabled clarification and consensus of components in the framework. Figure 1 depicts contributions to the draft framework. Expert stakeholders accepted the completed framework as a true reflection of discussions.

### ***Theory-of-change logic model components reflected in the framework***

A theory-of-change logic model consists of the following components: the problem the programme wants to solve, the community needs or assets related to the problem, desired results or vision for the future, factors that may influence programme changes, reporting on best evidence used in similar communities, and underlying assumptions regarding whether the programme will work (Breuer et al., 2016; Clarke & Braun, 2013; Harries et al., 2014). The theory-of-change logic model guided the framework of mHealth initiatives to support caregivers of adolescents with mental health issues (the programme) that was developed, and the components of the validated framework reflect those of the theory-of-change logic model. Underlying assumptions convey if a programme is likely to work (McLaughlin & Jordan, 2015; Mertens & Wilson, 2019) in a theory-of-change framework (Child et al., 2015). The authors assumed that an mHealth initiative would, indeed, support rural caregivers of adolescents with mental health issues. Another assumption was that the involvement of the

Department of Health is essential in the success of such a framework; the Department would either establish a new mHealth initiative for rural caregivers or integrate with existing mHealth initiatives in healthcare.

The *problem* or issue the framework intends to solve (McLaughlin & Jordan, 2015; W.K. Kellogg Foundation, 2004) should be clearly defined (Rogers, 2014). The reported framework's problem was that rural caregivers experience inadequate support when caring for adolescents with mental health issues. During the validation workshop, the expert stakeholders agreed on the problem statement that had been identified.

*Community needs* relate to what needs experienced by the community led to the framework development elicited by the problem (Mertens & Wilson, 2019; W.K. Kellogg Foundation, 2004). Community, in this framework, refers to caregivers of adolescents with mental health issues. Expert stakeholders expanded on community needs identified from the empirical evidence, and these needs are presented in the framework (see Figure 1).

*Desired results*, including outputs, outcomes, and impact, should be clearly stated when a theory-of-change framework is structured (Knowlton & Phillips, 2013; W.K. Kellogg Foundation, 2004). Changes in the target population's behaviour, skills, knowledge, attitudes, and self-efficacy are some of the outcomes intended by a framework (Mertens & Wilson, 2019). These intended results offer a vision of the framework's future or changes that are expected to occur in the community (McLaughlin & Jordan, 2015; W.K. Kellogg Foundation, 2004). In addition to the list on the draft framework, expert stakeholders envisioned five additional outcomes to be achieved if strategies are implemented (refer to Figure 1, which shows the supplements).

*Influential factors* refer to factors that can either facilitate or obstruct change in the community after implementing the framework (Ebenso et al., 2019; Mertens & Wilson, 2019;

W.K. Kellogg Foundation, 2004). A broad list of possible support and barrier factors affecting the mHealth initiative was identified through empirical evidence, which was confirmed by stakeholders.

*Evidence-based strategies* portray the actions needed to accomplish the desired results (Mertens & Wilson, 2019; W.K. Kellogg Foundation, 2004). The expert stakeholders were, in general, satisfied with the strategies mentioned, but decided to add a strategy. See Figure 1 for the additional strategy. This validation of the framework ensured its' credibility strengthening the development thereof.

### ***Methodological integrity***

Methodological integrity is central to determining the quality and legitimation of activities undertaken during the research process (Frels et al., 2015; Onwuegbuzie & Collins, 2007). Teddlie and Tashakkori (2009) suggest *inference quality* as a concept for appraising mixed methods research studies for quality. Inference quality requires processes to determine internal validity, trustworthiness and credibility in mixed methods research. Inference quality relies on two components, *design quality* and *interpretive rigor*, to ensure research integrity. Design quality represents methodological integrity, and interpretive rigor refers to credibility in the interpretation of results and conclusions (Onwuegbuzie et al., 2011; Teddlie & Tashakkori, 2009). The researchers used appropriate designs (design quality) applicable to each phase's objective, data collection, and data analyses, by capturing meaningful conclusions that enhance the quality of the research process (interpretive rigor). The quality of a draft framework can be assessed according to a checklist recommended by the W.K. Kellogg Foundation (2004) to determine whether the stakeholders understand the Theory-of-change's model's logical flow (Newcomer et al., 2015), which alternates through a forward

and backward mapping process (Hoppe, 2018). A hard copy of the framework was sent to the workshop experts for final verification, to ensure data authenticity.

## Results

A framework, which was developed for an mHealth initiative to support caregivers of adolescents with mental health issues, was accepted after consultation and validation with stakeholders. This framework illustrates the theoretically produced components of the phased approach, as well as stakeholder contributions. Figure 1 presents the final framework.<sup>2</sup>

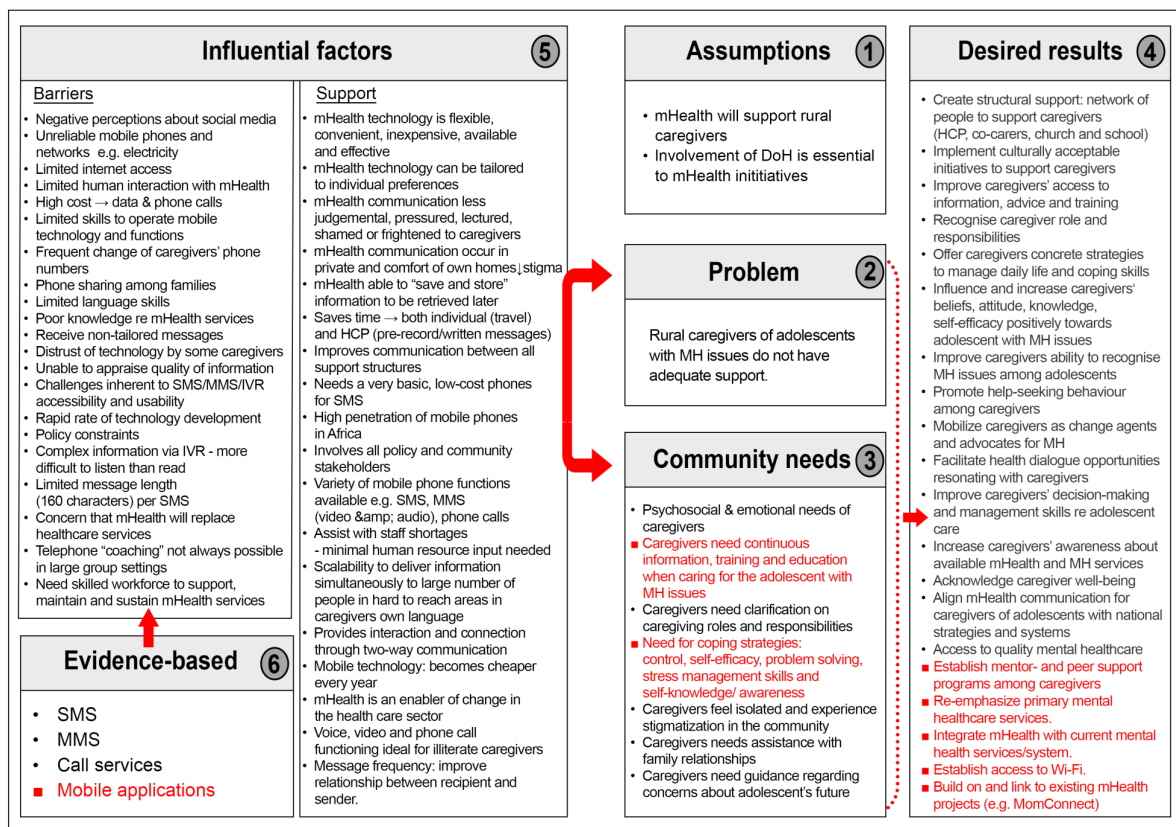


Figure 1: An mHealth communication framework for rural caregivers of adolescents with mental health issues

<sup>2</sup>•Reflects the contributions of the draft framework presented to expert stakeholders.

## *Discussion*

This article reports on the processes related to the framework development towards an mHealth initiative to support rural caregivers of adolescents with mental health issues. A framework could optimise the effectiveness of caregiver programmes, enhancing both caregivers and care recipients' outcomes (Van Houtven et al., 2011). Positive outcomes are related to the impact of the initiative on caregivers' behaviour. A change in caregivers' behaviour, for example, knowledge, skills and attitude, could be a result of the initiative's effectiveness (Mertens & Wilson, 2019).

Frameworks may portray a more intricate understanding of the program planning, goals, inputs, actions, outcomes, and underlying change impacting the process of implementation (Ebenso et al., 2019; Issel & Wells, 2018). Such a framework illustrates the pathways to change (Dhillon & Vaca, 2018; Ghate, 2018) that are central to programme implementation, by explaining how components collectively contribute to achieving the intended results (Bartholomew & Mullen, 2011; Clapham et al., 2017; Mertens & Wilson, 2019). A theory-driven approach informed the development of the framework in this research study.

All findings jointly captured empirical evidence reflecting the need for a framework towards an mHealth initiative to support caregivers. This need drove the authors to approach expert stakeholders to participate in a validation workshop for enriching the developmental process. Knowledge exchange between stakeholders with practical expertise and researchers with theoretical expertise could produce a plausible programme (De Silva et al., 2015). The participatory nature of the workshop generated an opportunity for expert stakeholders to engage in an open dialogue to contextualise the framework. Expert stakeholders' unique contribution confirmed the merit of the content quality of the framework. Active involvement

of expert stakeholders during framework development may ensure their buy-in (Breuer et al., 2014; Mason & Barnes, 2007) when the mHealth initiative needs to be implemented.

Consensus building among stakeholders and researchers supports a collaborative approach (Aromatario et al., 2019; Clapham et al., 2017), thereby adding meaning to the framework.

However, De Silva et al. (2015) claim that stakeholders' 'ownership' of the framework might be jeopardised, since researchers created the framework. The discussion will highlight the contributions to the framework that were made by the stakeholders after consensual agreements during the workshop.

Stakeholders were identified and selected due to their expertise, knowledge, and practical experience in family, child, and adolescent mental health settings. Due to their familiarity with working in these settings, the stakeholders shared a mutual concern about caregivers experiencing inadequate support in rural communities. Producing empirical evidence is fundamental to analysing and identifying the problem of a framework that needs to be solved (Aromatario et al., 2019; Davidoff et al., 2015; Ghate, 2018; Mertens & Wilson, 2019), as was the case in the reported study. Confirmation of inadequate support initiatives for rural caregivers was the driving force behind framework development. Tilahun et al. (2016) and Talley et al. (2014) confirm the urgency of developing initiatives to support families and children with mental health issues in resource-constrained communities, which should address their unmet needs.

Likewise, the nature of the caregiver support initiative may be influenced by the care recipient's condition (Van Houtven et al., 2011). Caregivers experience many challenges when caring for adolescents with mental health issues, and in regard to which they require support (Ae-Ngibise et al., 2015; Leventhal, 2018; National Academies of Sciences,

Engineering, and Medicine, 2019). **Caregivers' needs** listed on the draft framework were psychosocial, emotional, informational, educational, training, need for role clarification, need for coping strategies, need assistance in family relationships and guidance regarding the adolescent's future. The expert stakeholders decided that the adjective *continuous* should be added to emotional, informational, educational, and training support when caring for adolescents with mental health issues. Continuous support produces constant change, along with learning (Doubt et al., 2018), and endorses positive results (National Academies of Sciences, Engineering, and Medicine, 2018). It seems reasonable to provide more sustainable support rather than a solitary exercise to address caregivers' needs. Wodehouse and McGill (2009) reports that families value continuous support that is dependable.

Stakeholders also expanded on coping strategies by adding *self-knowledge/awareness* to the different coping skills. Chadda (2014) identified the need for healthy coping skills among family caregivers, and Cavaleri et al. (2011) confirm that caregivers of children at risk of emotional or behavioural problems should be supported with coping skills.

Initially, if the programme is going to be implemented, it is vital to understand the needs of the community and to align it with the **desired results**. The desired results entail the vision that developers have in mind for the community, as the beneficiaries of the initiative.

Expected behaviour or practice changes by the beneficiaries should arise as a result of the initiative implementation (Ghate, 2018; Ghate & Moran, 2013; Hayes et al., 2011; W.K. Kellogg Foundation, 2004).

All the expert stakeholders noted a lack and need of peer support by caregivers, as well as a shortage of mentoring programmes. They recommended to '*establish mentor and peer support programmes among caregivers*', raising an important issue that is well documented

in the literature. Caregivers who have higher demands, who care for recipients with challenging conditions, and who have access to minimal resources, are in dire need of support (Fernandes & Angelo, 2016; Friedman et al., 2018; Huus et al., 2017). Furthermore, inadequate support for families who care for adolescents with mental health issues is detrimental to those families (National Academies of Sciences, Engineering, and Medicine, 2016). Lauckner and Hutch (2016) list further challenges in rural communities, namely, social isolation, deficient communication and information, and lack of social support. Such challenges force caregivers to join informal support structures that may not be able to give adequate support; hence, the need to collaborate with healthcare professionals to offer adequate support to caregivers (Diehl et al., 2010).

Hilty et al. (2015; 2017) propose using mHealth technology for support groups or joining a support 'community'. Such groups aim to provide peer support by exchanging answers, tips, knowledge, or perspectives. Social support is an amalgamation of inspiration, collaboration, and guidance among peers, made possible through mHealth technology (De la Pena & Amezcua, 2017). A sense of belonging is created through group participation and sharing information on coping skills. However, the quality of the information shared could be questionable.

Mentors, due to their own experiences in caregiving, may assist in supporting and advocating for other caregivers. They could deliver training, resources, referral requirements, and lead support groups for caregivers (Horn, 2010). Abbott et al. (2019) define peer mentors as individuals who share similar encounters or programmes. These mentors provide emotional support and build capacity through building trusting relationships. Online support groups

could help to connect caregivers with peers or mentors who share similar circumstances, such as isolation or challenges related to a care recipient's behaviour.

Behaviour change could be optimal if ongoing peer or professional support follows the initial programme (Butler et al., 2019). mHealth technology can address the challenges experienced by caregivers, by supporting them through the provision of social support (Friedman et al., 2018), thereby improving their well-being by being motivated by peers (Dombestein et al., 2019). Building social support through mHealth initiatives for rural caregivers may promote positive attitudes and relationships with healthcare professionals working in primary care (Duppong-Hurley et al., 2016; Kutash et al., 2013).

The general feeling of the workshop participants that mental healthcare in primary healthcare should be scaled up vigorously by *'re-emphasising primary mental healthcare services'*.

After the advent of democracy in 1994, South Africa attempted to improve the primary care infrastructure by adopting a National Health Insurance Plan (Department of Health, 2015, 2016). This model aimed to provide universal care that was free to all citizens using public healthcare clinics in communities (Bresick et al., 2019; Dookie & Singh, 2012). Primary healthcare serves as the initial entry of healthcare into communities and it should, therefore, incorporate a comprehensive model of healthcare (Shidhaye et al., 2016), including mental health. Integrating mental health into primary healthcare is fundamental to managing individuals holistically.

Developing collaboration between and raising awareness in policymakers working to build capacity are ways suggested to strengthen mental health systems (Hanlon et al., 2018).

Wakida et al. (2018) identified vital components that necessary for integrating mental health into primary healthcare. These components, namely, suitability and reliability of the

programme, knowledge and skills, motivation to change, leadership and management, and financial resources, could act as barriers or facilitators in the implementation of mental health into primary healthcare.

The World Health Organization and UNICEF (2018) released the Astana Declaration on Primary Health Care after global consultation with experts from World Health Organization member states. The rationale for this declaration was based on *A Vision for Primary Health Care in the 21st Century*. This vision document provides insight into how primary healthcare can commit to health and well-being for all by capitalising on new technologies, resources, partnerships, and opportunities. The authors optimistically brought key expert stakeholders together to be mobilised as partners in the healthcare sector, to collaborate and possibly steer programme implementation. Stakeholder partnerships are a resourceful way to share knowledge and expertise (UNICEF, 2019) and identifying solutions for integrating mental healthcare into primary healthcare (V. Patel et al., 2016).

Docrat et al. (2019) reflect on mental health resources that are unevenly allocated and insufficiently used across South Africa, which contributes to inadequate mental healthcare (V. Patel et al., 2018). Improved access to mental healthcare could be achieved by investing in primary and community-based integration of mental health, thereby complying with global recommendations (Docrat et al., 2019), as well as recommendations to include mental health in the Sustainable Development Goals (United Nations, 2016). It is imperative to integrate mental health in primary care delivery that encompasses appropriate resourcing, sufficient governance, effective policies, healthcare delivery via technologies (Shidhaye et al., 2016), and political will (Hyman et al., 2016), to ensure intended health outcomes.

Expert stakeholders further discerned that ‘*mHealth initiatives should be integrated into the current mental health services*’ offered in primary healthcare. mHealth has opened new frontiers, by offering innovative healthcare delivery by empowering consumers (Hategan et al., 2019; Hilty et al., 2017; 2015) through various applications, such as prevention, observation, treatment, and support (Malvey & Slovensky, 2014). However, mHealth interventions should not replace customary primary care services, but only be used as a supplementary tool (V. Patel et al., 2018). Mobile technologies can influence individual, community, and population healthcare practices and ensure improved health behaviour (Hall & Bierman, 2015; Kahn et al., 2010), including mental health outcomes. mHealth showed promise in transforming healthcare by employing a mobile device (Avgar et al., 2012; Istepanian & Woodward, 2017). The exponential evolution of mobile phones in low and middle-income countries harnessed promising solutions for healthcare delivery (Ellery & Ellery, 2012; Källander et al., 2013; Marin et al., 2017), information delivery (Danis et al., 2010; Delponte et al., 2015), health prevention and support (Malvey & Slovensky, 2014), behaviour change communication (Labrique et al., 2013), health education (Free et al., 2013) and training (Kumar et al., 2013) to the end user.

Naslund et al. (2017) describe technology usage in mental healthcare through mHealth in resource-constrained areas as involving diagnosing, screening, managing, preventing, training of, and promoting self-management by individuals. mHealth functionalities may link to services provided in primary healthcare clinics. Changes in mental healthcare could likely be achieved through mHealth technology (V. Patel et al., 2018). South Africa published *The National Digital Health Strategy for 2019 – 2024* to establish structures, platforms, broadband networks, and information systems to strengthen digital health in conjunction with

various stakeholders (Department of Health, 2019b). Intensifying efforts to incorporate mHealth technology in mental healthcare delivery should be a focus of relevant stakeholders, governance, and policymakers. In South Africa, *The Ideal Clinic Initiative* was launched to tackle shortcomings influencing quality in primary healthcare services. One feature of this initiative is to provide adequate information and communication infrastructure, hardware, and Internet access (Department of Health, 2018).

The expert stakeholders said there is no need to ‘reinvent the wheel’ for developing a new initiative if one can ‘*build on and link to existing mHealth projects (e.g., MomConnect)*’, which is currently being implemented in primary healthcare by the Department of Health. Making use of existing infrastructure and available resources can strengthen the proposed mHealth initiative framework for rural caregivers. Khatun et al. (2016) identified a number of problems affecting mHealth usage in the community. One such problem is that the community is not knowledgeable about mHealth services.

Stakeholders, in this case, were aware of mHealth services and discussed two exemplary projects currently utilised by the Department of Health, namely, MomConnect and Project Masiluleki. MomConnect is a mobile messaging service that supports maternal health through mobile phones and interaction with a helpdesk. It enables pregnant women or mothers of infants to receive free informational messages in all 11 official South African languages (LeFevre et al., 2018; Xiong et al., 2018). Education regarding accessible prenatal and postnatal services was offered, and provisions were made to give feedback (Department of Health, 2019b). MomConnect, as a flagship Department of Health programme, could be extended to other user groups, types of conditions, and management as well as healthcare professionals. Piggybacking on a successful project like MomConnect may be worthwhile to

consider. Efficient Department of Health leadership facilitated the MomConnect process, in collaboration with skilled content and technology developers (Barron et al., 2018).

Another landmark in South Africa is Project Masiluleki – meaning ‘lend a helping hand’ in isiZulu – which provides opportunities to change behaviour. This project focuses on encouraging individuals to test for HIV and tuberculosis, and to take their medication. It is a ‘Please call me’ initiative, whereby callers connect with a government-operated helpline to receive culturally relevant information in several local languages (Källander, 2010; PopTech, 2011) The expert stakeholders perceived these distinguishing projects to be strong points of reference that could guide the implementation of the current framework.

Expert stakeholders elaborated further on the desire ‘*to establish Wi-Fi access*’, and raised valuable concerns related to connectivity that may influence the implementation of the framework initiative. According to the National Digital Health Strategy of South Africa (Department of Health, 2019b), it is important to evaluate information systems across the health sector to determine functionality and connectivity and, moreover, to resolve any connectivity barriers impeding steps taken by South Africa to digital health operationalisation. Issuing guidelines for broadband infrastructure distribution in South Africa have been delayed (Gillwald et al., 2018).

Network connectivity is a real concern in developing countries, and impacts future mHealth initiative implementation (Istepanian & Woodward, 2017). Less than half of South Africa’s rural population has Internet connection, suggesting digital inequality between rural and urban residents. Internet connectivity is impacted by the income of the users (Gillwald et al., 2018). In the least developed countries, only 15% of homes have Internet connections (ITU, 2017). The World Health Organization (2019) recommends that systems should be created to

ensure connectivity infrastructures. South Africa's mHealth strategy (Department of Health, 2019a) aims to provide ICT platforms and network connections at primary healthcare clinics. Inadequate income, poor infrastructure, and deficient Internet connectivity will play a role in the implementation of the framework. These determinants should be kept in mind when deciding on the strategy chosen for the framework, as it was also mentioned under influential factors as barriers to change. Naslund (2017) argues that improving connectivity could resolve the healthcare gap in remote areas. The link between influential factors (barriers and support) and proposed strategies is acknowledged in the framework.

The expert stakeholders identified one more **strategy** they believe will help achieve the desired results discussed. Strategies are identified and chosen on the assumption that behaviour change will occur (Knowlton & Phillips, 2013). The authors provide evidence-based strategies that were identified from literature that had studied populations similar to that of the current research. The strategies that were selected for the framework aim to support caregivers during caregiving, and anticipates behaviour change as the intended impact of the research study.

Overall, the expert stakeholders agreed about the selected strategies (SMS, MMS, and call services), but suggested including *mobile applications* as a fourth strategy for supporting rural caregivers. Mobile applications can be used to disseminate content (Scolari et al., 2012) and to provide support (Källander et al., 2013). SMS and calendar applications are embedded in basic mobile phones, while WhatsApp demonstrates a more complex application that runs on smartphones (Baig et al., 2015; Klasnja & Pratt, 2012).

The possibilities of mobile applications in rural healthcare are prodigious (Chand et al., 2016; Laidlaw et al., 2017), and exhibit improved healthcare delivery through various mobile

channels (Free et al., 2013). Botha and Booii (2016) reviewed current mHealth applications implemented in South Africa. They found most apps supplied educational information for the general public with the aim of promoting behaviour change. One of the challenges experienced in South Africa regarding mHealth projects is a lack of practical approaches, frameworks, and interoperability (Department of Health, 2019a). Improving broadband access and Internet connectivity may improve the use of mHealth initiatives in rural areas (Betjeman et al., 2013). Scaling up mHealth initiatives should be a focus of governance, leadership and legislation, among others, and stakeholder involvement could ameliorate the infrastructure in rural areas (Department of Health, 2019b). If people have mHealth and mobile phones at their disposal, rural populations have opportunities to access support (Chan et al., 2014).

Initiatives offering support have the potential to relieve caregivers' burden and improve their well-being (Fernandes & Angelo, 2016; Talley et al., 2014). It is, therefore, crucial to develop support initiatives that are appropriate to caregivers' individual needs (Chang et al., 2016). The framework visualises a roadmap to achieve the planned mHealth, by explaining causal relationships between all the components. The theory of change was considered to be an essential building block for drafting the framework and developing an mHealth initiative that supports rural caregivers.

### ***Strengths and limitations***

Specific strengths of the study are worth noting. A combination of empirical evidence, the theoretical foundation of framework planning, active engagement, and consensus among expert stakeholders ensured the methodological rigor of the study. Consensus by multiple stakeholders during the validation workshop ensured plausible confirmation of research

procedures –stakeholders agreed on the conclusions drawn by the researchers. Formation of stakeholder partnerships during the workshop reflected future collaboration in the implementation of the framework initiative. Another strength of this study is that, due to stakeholder participation, the framework could be incorporated into the communication component of The Ideal Clinic initiative being driven by the Department of Health.

The authors acknowledge that not all stakeholders were familiar with the methodology of the study. However, interactive discussions limited possible interpretation errors of the framework. Since the framework focused on a specific rural area in South Africa, generalisability is limited.

### ***Conclusion***

The proposed framework is constructed from integrated, evidence-based data characterizing the distinctive theory-of-change components logically. Transparency in the development process constitutes a believable approach to how the framework could support rural caregivers through an MHealth initiative.

One should understand how the framework activities are expected to bring about the desired results for rural caregivers of adolescents with mental health issues. A successful framework is determined by the intended results secured by the chosen strategies (Knowlton & Phillips, 2013; W.K. Kellogg Foundation, 2004). “*Knowing where you are headed is critical to picking the best route to use*” (Knowlton & Phillips, 2013). This quote explains the vision of the researchers for the current framework.

Realising this vision is not possible without collaboration and partnerships between academia, healthcare professionals, and government officials. Collaboration has the potential to guarantee the successful implementation of the framework for supporting a vulnerable

population. Extending healthcare from conventional services to digital platforms may leverage opportunities to transform healthcare delivery. Providing healthcare access to all, including populations in remote areas, fits in well within the re-engineering of primary healthcare services, as well as The Ideal Clinic objectives. Neither should we forget about the role non-profit organisations, corporate businesses and religious associations could play in supporting rural caregivers.

Rural caregivers must have access to ongoing support initiatives that meet their specific needs. Due to high mobile phone penetration among resource-constrained populations, mHealth may be the ideal solution for meeting caregivers' unmet needs. Support initiatives that are provided through mobile technology offers a vehicle to deliver targeted healthcare solutions to caregivers. Boosting caregivers' well-being through targeted support initiatives will be a key determinant in changing caregiver behaviour positively. A change in caregiver behaviour may lead to improved adolescent mental health outcomes. Using a supportive mHealth initiative may strengthen caregivers' behaviour and influence their caregiving practices positively, which would reflect in improved mental health outcomes for adolescents.

### **Abbreviations**

eHealth – electronic health  
ICT – information and communication technology  
IMBP – Integrated Model of Behaviour Prediction  
mHealth – mobile health  
MMS – multimedia messaging  
SMS – short message service

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## Authors' contributions

RJ performed the data analysis and data integration, and prepared the draft framework. MR facilitated the validation workshop and provided key methodological expertise for the process. RJ drafted the manuscript. MR revised the manuscript critically and approved the final framework. Both authors read and approved the final manuscript.

## Competing interests

The authors declare that they have no competing interests.

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## CHAPTER 7: CONCLUSIONS AND IMPLICATIONS

*"Our most urgent need is not for a master plan for all communities but for plans that are based on the views and needs of the people, developed with the people and subject to modification by the people."*

*-Patrick G. Boyle<sup>8</sup>-*

### 7.1 INTRODUCTION

In this chapter, the researcher will critically reflect on the study as a whole and discuss a number of conclusions reached and their implications, based on the results of the study. Firstly, the researcher will recap the problem statement, aim, research questions, and the chosen methodology that guided the research process. Factual, interpretative, and conceptual conclusions will then be presented, as will the summary of the components in the final framework. Following that, the researcher will introduce implications for theory, practice, and future research. Lastly, the limitations of the study and contributions made by the researcher will conclude this chapter.

### 7.2 SUMMARY OF THE PROBLEM STATEMENT, RESEARCH QUESTIONS, AND STUDY AIM

Family members are generally the primary caregivers of children and adolescents. Caring for an adolescent may be challenging, due to the typical formation of mental health issues associated with rapid transitions, and developmental problems arising during adolescence (Toska et al., 2019; Finan et al., 2018). Caring for adolescents suffering from mental health issues is burdensome to caregivers (Gérain & Zech, 2018; Dada et al., 2011); these caregivers are more prone to experience subjective and objective burdens (Gérain & Zech, 2018; Flyckt et al., 2015; Talley et al., 2014), thereby creating a situation in which various support needs are not met (Oruche et al., 2017; Talley et al., 2014). Unmet support needs could influence the caregiver and the adolescent's well-being (Brazil et al., 2014).

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<sup>8</sup> Boyle, P.G. 1981. *Planning better programs*. New York: McGraw Hill.

Even more concerning is those needs of caregivers and adolescents living in rural areas with no or limited support and access to mental healthcare services (WHO, 2017a). Rural caregivers lack support initiatives targeting their unique needs related to caring for adolescents with mental health issues (Steding, 2016). Initiatives to support caregivers are of increasing importance because of the challenges they face in their caregiving practices. Suitable initiatives may strengthen caregiver behaviour, making it more positive and improving their attitudes, norms, self-efficacy and skills (Corralejo & Rodríguez, 2018).

Emergent mHealth initiatives demonstrate promising results (WHO, 2018b; Davis et al., 2016) supporting rural caregivers in resource-constrained environments (Anderson-Lewis et al., 2018; Chand et al., 2016). Involving caregivers in the planning of such initiatives is arguably a positive step forward and, thus, it is important to understand caregivers' perspectives regarding mHealth. Another critical determinant related to planning mHealth support initiatives is developing a framework to guide the planning process (Davis et al., 2016), in order to demonstrate how caregivers' behaviour could change. A systematic planning approach that details the activities of behaviour change may be visualised through a framework.

The main aim of this study was to develop an mHealth communication framework for rural caregivers of adolescents with mental health issues in the Kopanong local municipality. The researcher sought to answer the following question: *What should an mHealth communication framework that is to be used by rural caregivers of adolescents with mental health issues in the Kopanong local municipality consist of?* This question was trailed by three objectives to address the aim of the study.

- To explore rural caregivers' interest in using communication technology to provide support addressing their challenges (Phase 1).
- To systematically review the literature on the best evidence available to strengthen positive behaviour of caregivers of adolescents with mental health issues using communication technology (Phase 2).

- To describe the development of an mHealth communication framework for rural caregivers of adolescents with mental health issues in the Kopanong local municipality (Phase 3).

### **7.3 METHODOLOGY**

A multiple method research design (Polit & Beck, 2018; Hunter & Brewer, 2015), rooted in pragmatism as the philosophical underpinning, was deemed appropriate for addressing the research questions. An overarching question with subsidiary questions requiring different research approaches is useful in multiple methods designs (Teddlie & Tashakkori, 2009). The researcher believed that her research question and related objectives would be answered best by using multiple methods and incorporating a pragmatic stance. As a pragmatist, the researcher actively undertook suitable data collection methods that addressed the research question.

Developing an initiative to support caregivers should be based on evidence, theory, literature review, participant data, and expert stakeholder involvement (Fernandez et al., 2019) that reflects the interactions among these components (Craig et al., 2019), which characterise a complex intervention. It was best to conceptualise this study as the developmental phase of a complex intervention presented by the Medical Research Council of the United Kingdom (Craig et al., 2019). The theory-of-change logic model guided the developmental phase of the communication framework, while the IMBP conceptualised the programme to provide support to caregivers. A phased approach was thus adopted to inform the development of a complex intervention.

This study harnessed a phased approach to develop an mHealth framework for caregivers of adolescents with mental health issues. Phase 1 employed a visual-based narrative inquiry to explore caregivers' interest in using communication technology when caring for adolescents with mental health issues. Phase 2 involved a systematic review that searched for the best evidence available to strengthen the positive behaviour of caregivers of adolescents with mental health issues using communication technology. Phase 3 consisted of a workshop that validated the

proposed framework for the development of an mHealth initiative to support caregivers of adolescents with mental health issues.

The IMBP (Fishbein & Yzer, 2003) was adopted to guide the conceptualisation during each phase. Conceptualising determinants of behaviour (attitudes, perceived norms, and self-efficacy), together with skills and environmental constraints, described the influence on caregivers' behaviour. The IMBP also served as a foundation to improve understanding of the intention-behaviour relationship relating to whether caregivers would be likely to engage with mHealth communication technology, consequently, influencing their caregiving behaviour positively if they do use mHealth communication technology.

All the evidence generated from the three phases allowed the researcher to identify specific findings. These findings were used to draft the framework informing the development of an mHealth initiative for rural caregivers. This draft framework was validated by the expert stakeholders and finalised during the workshop.

## **7.4 FACTUAL CONCLUSIONS**

Factual conclusions describe facts derived from evidence in data collected during the research process (Trafford et al., 2014). Factual conclusions based on the evidence from each phase will be presented.

### **7.4.1 Phase 1**

Individuals assume a caregiving role voluntarily or involuntarily, formally or informally. The care recipient's characteristics, their condition or issue, and the setting in which caregivers deliver care, challenge their caregiving roles. Certain factual conclusions could be made from the findings of Phase 1. Caregiver challenges were captured in three themes and relevant subthemes, while a fourth theme represented their interest in communication technology offering a possible solution to receiving support. *Psychosocial challenges* included four subthemes, namely, their well-being, roles, beliefs, and personal control.

Their *social resource challenges* involved three subthemes, that is, relationships, support services, and external challenges. The third theme described their *informational challenges* through two subthemes, resources, and the adolescent's behavioural issues. The fourth theme portrayed caregivers' *interest in communication technology* as presenting a possible solution to challenges they experienced and indicated their communication technology preferences. These caregivers preferred SMS, phone calls, and using a computer to access information.

#### **7.4.2 Phase 2**

The systematic review aimed to articulate if using communication technology strengthens caregivers' behaviour positively when they care for adolescents with mental health issues.

The researcher formulated three thematic conclusions after the data of the five included articles had been analysed and synthesised. Thematic conclusion 1 involves *the types of communication technologies* described in the articles that were included. Communication technology used in these studies was web-based interventions, and they used social media, email, phone calls, text messages, and online formats to communicate with target populations. The target population gave positive feedback regarding the use of communication technologies, though the focus was not on caregivers' experiences of the different types of communication technologies.

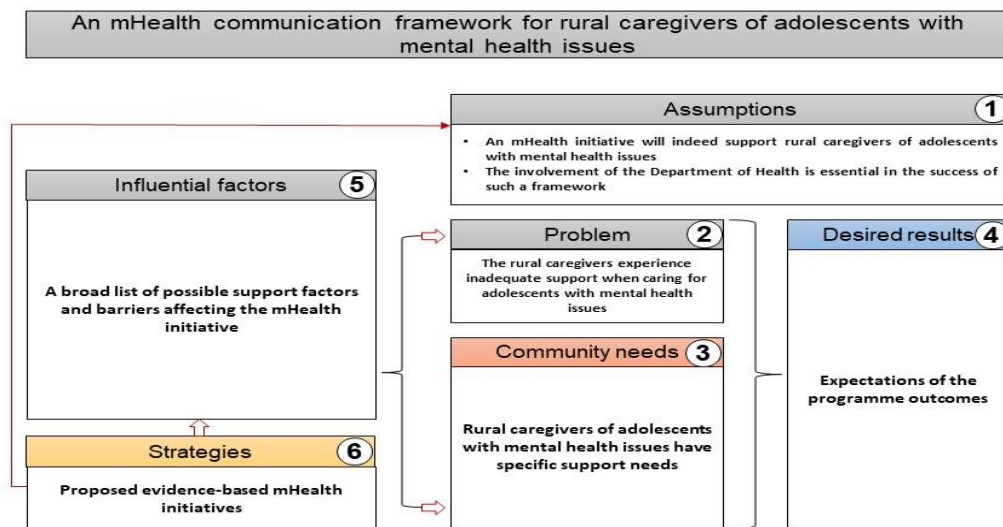
Thematic conclusion 2 summarises *the target population* depicted in the five articles that were included. This population consisted of parents, caregivers, or family members of adolescents with mental health issues. The third conclusion focused on *the IMBP determinants* presented in the outcomes of the five articles that were included. These IMBP determinants may explain the strengthening of positive behaviour in a practical way. Specific IMBP determinants described in the five studies were caregivers' self-efficacy, which showed an improvement, better communication skills between the caregiver and adolescent, effective parenting skills, and increased knowledge of caregivers.

### 7.4.3 Phase 3

Phase 3 completed the research process. Expert stakeholders validated the draft framework during a workshop and contributed a few additional ideas to only three components on the draft, which demonstrated overall satisfaction with the framework. These expert stakeholders contributed to the following components: community needs, desired results, and evidence-based strategies, to finalise the framework. After consensus, the framework was finalised.

## 7.5 CONCEPTUAL CONCLUSIONS

Conceptual conclusions provide a reasoned understanding of the researcher's interpretation of the facts in alignment with the framework. **Figure 7.1** serves as a *point of reference to explain the conceptual conclusions based on the summary of the framework components* (source: W.K. Kellogg Foundation, 2004).



**Figure 7.1: Summary of the components in the final framework**

Meaningful interpretation of research findings helped the researcher to unfold conceptual conclusions (Trafford et al., 2014). The formulation of the conceptual conclusions will be discussed within the context of the theory-of-change logic model

framework components that imply that positive behavioural outcomes are linked to the IMBP determinants.

Using a range of appropriate data collection techniques ensured triangulation of evidence, which exhibits the *context* of the proposed mHealth initiative portrayed in the framework. Information ranging from the local perspectives of rural caregivers to available literature served as contextual evidence in the planning of this framework. This study revealed a framework that proposed a programme to support rural caregivers of adolescents in the Kopanong municipality. Supporting caregivers of adolescents with mental health issues (programme) through an mHealth initiative may be contextually influenced. We can conclude that a better understanding of the caregivers' context enabled the researcher to develop a framework in answer to the problem statement. A limited understanding of caregivers' context leads to inadequate consideration of the influential factors that could possibly affect a programme.

The researcher had to pay attention to the contextual factors as the embeddedness of the *problem statement*. Through exploration, the problem helps to build the partnerships needed to make change a reality, as articulated in the framework. In clarifying the caregivers' context, it becomes possible to bridge the gap between the problem and the planned framework. Based on the findings derived from multiple research methods, evidence confirms the relevance of the problem statement indicated by the researcher. It can be concluded that the framework has the potential to address the problem of inadequate support experienced by rural caregivers of adolescents with mental health issues. The final framework is grounded in the caregivers' reality, as part of the problem is living in a resource-constrained setting without any support.

Findings from the three phases outlined the caregivers' *needs*. It became evident in the findings that caregivers (the community) need support. The study recognised that the resource-constrained environment cannot be separated from caregivers' needs. Furthermore, it became clear that a programme that is planned to address unmet support needs should benefit rural caregivers. Developing an mHealth

communication framework was intended to address the gap between rural caregivers' unmet needs and providing support through an mHealth initiative. To conclude, if a framework for an mHealth initiative could be used to support rural caregivers, it could improve caregiving behaviour in relation to caring for adolescents with mental health issues.

Evidence from the study suggests that the *desired results* that were expected are based on caregiver behaviour. This implies that, if the programme is effective, there is an expectation, based on various outcomes depicted in the framework, that caregiver behaviour will change and become more positive towards the adolescent. Though individuals may have different desires related to outcomes and expectations, the researcher concludes that all stakeholders shared similar visions constituting the desired results.

In articulating the desired results, the *influential factors* should be borne in mind. Such factors might affect the success of the programme, in either a positive or a negative way. The study's findings indicate that the caregivers are interested in an mHealth initiative; however, influential factors can play a role in the success of such an initiative in a resource-constrained environment. All possible influential factors that could serve as either barriers or facilitators were documented in the framework. The conclusion here is that a framework for rural caregivers may contribute to successfully supporting them if facilitating factors are strengthened, and barriers are minimised.

As the study indicates, various *evidence-based strategies* related to communication technology have been found to be useful in supporting rural caregivers. The findings of the study discussed mHealth strategies that have proven viable for caregivers in resource-constrained settings. These strategies are outlined in the framework as evidently the best way to achieve the desired results. We may conclude that the suggested strategies will support the rural caregiver during caregiving practices in achieving the desired results associated with positive behaviour linked to the IMBP determinants.

The researcher assumed that an mHealth initiative, in collaboration with Department of Health stakeholders, would support rural caregivers. Through this research, evidence from findings confirmed these assumptions made by the researcher. These assumptions could influence whether the programme will accomplish the desired outcomes. These assumptions were made explicit by the researcher during the workshop that was validated by the expert stakeholders. It can, thus, be concluded that assumptions made by the researcher were validated by the expert stakeholders that may possibly trigger some action to pilot the framework. Figure 7.1 summarises the component descriptions in the final framework.

## **7.6 LIMITATIONS**

A number of limitations of this study need to be considered and understood in the context of the findings.

One limitation was the small sample that was used for the empirical data collection, and the fact that the majority of participants were women in a specific rural setting in South Africa, which implies limited generalisability. This limitation suggests that additional research investigations should be undertaken into the interest in communication technology by rural caregivers of adolescents with mental health issues in other parts of South Africa, and among similar populations in other countries.

The systematic review did not generate information about specifically Black rural caregivers, who use communication technology in caring for adolescents with mental health issues, although the search string was all-inclusive. This under-representation of the target group in the current research posed some challenges for the researcher concerning generalising rural caregivers' use of communication technology influencing the IMBP determinants when caring for adolescents with mental health issues. As a way to address this limitation, the researcher engaged in a comprehensive literature search in Chapters 2 and 3, and focused on various components related to caregivers, adolescents with mental health issues, resource-constrained settings, caregiving behaviour and communication technology, and

solicited input from expert stakeholders who were knowledgeable about the study context.

## **7.7 IMPLICATIONS AND RECOMMENDATIONS OF THE STUDY**

The following section serves to point out several substantial implications derived from the conceptual conclusions. This study draws implications for theory, practice and future research, and makes related *recommendations*.

### **7.7.1 Implications for theory**

Investigation of the literature showed a lack of existing theory-of-change frameworks for rural caregivers of adolescents with mental health issues in South Africa. In this case, a theory-of-change logic model framework (Chapter 6) was developed, to support rural caregivers by using an mHealth initiative, while the IMBP served as the theoretical underpinning of the programme. This study is the first in South Africa to develop a framework for the development of an mHealth initiative through which caregivers of adolescents with mental health issues may be supported, consequently addressing the dearth of frameworks for initiating programmes for rural caregivers. With this in mind, this study carried out an iterative process to develop the framework and was guided by a theory of change, which is a crucial facet of intervention development, piloting, implementation, and evaluation in complex interventions.

Behaviour change requires a conducive environment. Environments might complicate an intervention that was described as an influential framework component as well as a background factor of the IMBP model. Environments are more changeable than behaviour and can be challenging in a resource-constrained setting. Indeed, the framework listed possible support factors or barriers to the strategies proposed. The proposed strategies are assumed to lead to the desired results, including change in IMBP determinants; however, the mentioned mHealth strategies need to be developed for a resource-constrained environment. This has implication for developers, who should tailor the proposed mHealth strategies according to the resource-constrained environment. If the environment does not

support the mHealth strategy, the expected results will be influenced, resulting in negative IMPB outcomes. Negative IMPB outcomes, will consequently, affect caregiving practices.

*Developing tailored mHealth initiatives targeted to caregivers support needs are recommended and might increase caregivers' utilisation of such initiatives. In addition, developers should consider focusing on one mHealth initiative that rural caregivers are already most familiar with in the piloting of the framework. Beyond this point, their interest in using a familiar mHealth initiative will guide the success of the framework. For example, launching a SMS mHealth initiative could be the first step in supporting rural caregivers in their caregiving practices.*

Supporting caregivers through an mHealth initiative may influence their caregiving practices and changing their skills, knowledge, self-efficacy, and attitudes towards the adolescent with mental health issues. The IMBP offers an understanding of the determinants that affect caregiving behaviour through the programme. This implies that, if the mHealth initiative (framework) supports the caregivers (the programme) sufficiently, then positive behavioural change (theory of change) is possible. Behavioural change may be reflected in the presence of positive behaviour that is demonstrated through the IMBP determinants.

*A suggestion is that the programme offers optimal support opportunities for rural caregivers through the PHC setting, that implies inputs by healthcare professionals, and church and school involvement, which could supplement mHealth initiatives and influence caregiver behaviour and practices.*

### **7.7.2 Implications for practice**

There is a lack of frameworks for supporting rural caregivers of adolescents with mental health issues through mHealth initiatives. This is the first step to bridge the gap. This study described the developmental phase that formed part of a complex intervention. Before this study's framework can be implemented, it should be tested for feasibility and piloting. The study points out that a collaborative approach by the public healthcare sector may foster commitment to support rural caregivers with

programmes delivered by mHealth initiatives. A practical implication is that the researcher, with the Department of Health as a key stakeholder, should start piloting this programme. Literature advises healthcare departments to tackle inadequate mental healthcare delivery and services in resource-constrained environments through task shifting at a primary care level (Javadi et al., 2017; Hanlon, 2016).

*A recommendation is that stakeholders could assist in the framework piloting of the mHealth initiative to support rural caregivers. Successful piloting and implementation of an initiative does not occur in isolation, but through collaboration with influential stakeholders from provincial and national departments of health, together with well-defined regulatory legislation and policy guidelines in the relevant sectors. Digital networks and access should be prioritised by the Department of Health, with special attention to the needs of resource-constrained settings. Furthermore, collaboration with rural caregivers, non-governmental and private organisations, local champions and leaders, and interprofessional team members should be considered; these collaborators could be partners in mobile healthcare delivery that targets rural settings.*

The services of a large cadre of PHC professionals are undermined by staff shortages, limited resources, and an increased burden of diseases, which is aggravated by limited mental health services and little expertise in rural settings. Communication technologies can be an essential resource in PHC for delivering mental healthcare to rural settings, though multi-sectoral stakeholder involvement would be required. Empowering caregivers through mHealth initiatives could be instrumental in mental health promotion and prevention, and increasing awareness of mental health issues among adolescents in resource-constrained environments.

*Another recommendation is that healthcare professionals ought to learn to be aware of the usefulness of mHealth initiatives for assisting with mental healthcare in PHC settings. These healthcare professionals could advocate for piloting of the mHealth initiative to be used for rural families in mental healthcare, thereby enhancing the adoption of mHealth technology in the public health sector. Healthcare professionals currently working in the PHC setting are already using mHealth applications in the*

*HIV, tuberculosis and maternity fields, though there is still a gap regarding delivering mental health services. In the end, initiating an mHealth framework that delivers programmes to rural caregivers of adolescents with mental health issues is likely to lead to independent caregivers, which would be beneficial, in light of staff shortages in rural PHC settings.*

To date, there has been limited research on the experiences, challenges and unmet needs of rural caregivers of adolescents with mental health issues. This study contributes to this knowledge by providing empirical findings and comprehensive literature reviews regarding these caregiver challenges and relevant unmet support needs. In addition, the Mmogo-method<sup>®</sup>, a culturally sensitive data collection technique, was used for the first time by the School of Nursing to collect valuable data from rural caregivers. Employing research techniques that resonate with rural participants and provide contextual rich data is a significant methodological contribution to nursing.

*A central theme of the thesis is the proposition that the support needs of rural caregivers of adolescents with mental health issues require individual attention and recognition, separate from the great deal of research available on other groups of caregivers. Healthcare services in rural settings could involve caregivers as partners in the care relationships, and acknowledge and support them. Supporting caregivers of adolescents with mental health issues should be explored further in research.*

Lastly, the framework resulted in collaborations with expert stakeholders from various fields relating to adolescent mental healthcare. Little was initially known about the Kopanong caregivers' viewpoints, or about literature presented to the stakeholders, who will all probably make valuable contributions to knowledge in the Department of Health. It is hoped that the Department of Health will recognise the urgent need to support the researcher in piloting the framework that will aim to support rural caregivers of adolescents with mental health issues.

*Lastly, communication technologies should not offer caregiver support programmes in isolation, but, instead, serve as complementary services presented by healthcare professionals in PHC clinics – current care provision should not be replaced.*

### 7.7.3 Implications for future research

There are a few possible implications that could be taken into account for future research. These implications consider various issues that emerged from the study and indicate new avenues of research.

In the light of this study, further research could explore rural adolescents' views of mental health issues, as well as their relational experiences with their primary caregivers. In addition, research should investigate rural caregivers' and adolescents' mental health literacy by means of standardised questionnaires. Such questionnaires could compare and describe these two populations' understanding and knowledge of mental health issues. Investigating the mental health literacy of caregivers and adolescents in South Africa will contribute to the current dearth of knowledge in the literature in this regard.

Knowledge gaps noted in the comprehensive literature search indicated a need for more robust studies in South Africa, either related to rural caregivers of adolescents experiencing a mental health issues, or adolescents with a confirmed mental health diagnosis, and the preferred method of communication technology. Furthermore, studying the feasibility and implementation of communication technology by caregivers in rural settings will enrich intervention development.

Lastly, future research needs to be done with relevant stakeholders after piloting the framework, to identify what they found to be the barriers or facilitators. This kind of research could lead the way to future implementation of the framework. Likewise, longitudinal research that involves healthcare professionals and families throughout the implementation process of the refined mHealth initiative after piloting could be valuable to explore later.

*One could suggest that healthcare professionals, especially nurses, ought to act as change agents in the field of caregiving and mental health services. Nurses should foster communities of practice among caregivers. By fostering communities of practice, collaboration could improve, as nurses could work together with caregivers and contribute to mental health promotion. This study calls for future work on*

*communities of practice between nurses and caregivers of adolescents with mental health issues.*

## **7.8 CONCLUDING REMARKS**

This study took critical steps to generate a framework for an mHealth initiative that supports rural caregivers of adolescents with mental health issues. Given the emergence of mHealth interventions in resource-constrained settings, this thesis demonstrated that mHealth could provide support to rural caregivers. Indeed, the study succeeded in addressing the aim of the research by answering the research question and sub-questions. In doing so, the study contributed to existing research by addressing the knowledge gap identified in Chapter 1.

The findings indicate that an mHealth initiative could support rural caregivers of adolescents with mental health issues in a resource-constrained setting. Furthermore, the study's findings provide an understanding of rural caregivers' challenges and unmet needs relating to their caregiving practices. Providing these caregivers with support through mHealth initiatives could have far-reaching benefits for both the caregiver and adolescent. Applying the IMBP theory to predict caregiver behaviour can help to strengthen caregiving practices. The theory-of-change logic model provides an anchor for developing a framework for supporting rural caregivers of adolescents with mental health issues, and who are pursuing positive behaviour change. A theory-of-change logic model approach proved to be adequate for mapping the complexity of a caregiver programme, especially for detailing the theory of change activities.

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# **ADDENDUM A**

POSTGRADUATE STUDENT AND PROMOTOR AGREEMENT  
FACULTY OF HEALTH SCIENCES  
UNIVERSITY OF THE FREE STATE

**POST-GRADUATE STUDENT AND SUPERVISOR AGREEMENT:  
FACULTY OF HEALTH SCIENCES  
UNIVERSITY OF THE FREE STATE**

In a context of academic freedom and within a framework of individual autonomy and the pursuit of knowledge this agreement is written in the belief that there is a reciprocal relationship and mutual accountability between supervisor and student.

(With acknowledgement to the University of the Witwatersrand:  
Statement of Principles for Postgraduate Supervision)

**The supervisor and the student will:**

1. Establish agreed roles and clear processes to be maintained by both parties. In the case of joint supervision, the role of every participant must be clarified.
2. Meet regularly and as frequently as is reasonable to ensure steady progress towards the completion of the proposal, research report, dissertation or thesis.
3. Keep appointments, be punctual and respond timeously to messages, and keep one another informed of any planned vacations or absences as well as changes in his/her personal circumstances that might impact on the work schedule. Unplanned absences or delays should be discussed as soon as possible and arrangements should be made to catch up lost time.
4. Ensure that research on animal or human subjects is conducted according to the procedures and the requirements of, and will prepare progress reports for the attention of the relevant University Ethics committee.



5. Discuss and decide on the publication of the results:

When will the draft manuscript be available for publication? (Please indicate with X)

- |                                   |                                     |
|-----------------------------------|-------------------------------------|
| (a) Before submission             | <input type="checkbox"/>            |
| (b) At submission                 | <input type="checkbox"/>            |
| (c) Three months after submission | <input type="checkbox"/>            |
| (d) Six months after submission   | <input checked="" type="checkbox"/> |

**Before the commencement of a project, there must be a clear written agreement entered into with a postgraduate student, which states that a concept manuscript will be prepared within six months after the final completion of the report/script/dissertation. Should the student not present a concept manuscript within this time, the study leader becomes the first author and the student the second author.**


**The supervisor will:**

1. Assist with the construction of a written time schedule outlining the expected completion dates of successive stages of the work.
2. Provide guidance for the research project in relation to the design and scope of the project, the relevant literature and information sources, research methods and techniques and methods of data analysis.
3. Be accessible to the student and will be prepared for meetings with the student. This includes being up to date on the latest work in his/her area of expertise.
4. Provide written comments, either in summarised form or annotated in the document, within a timeframe jointly agreed upon at the outset of the research – suggested time is two (2) weeks.
5. Provide advice that can help the student to improve his/her writing; provide guidance on technical aspects of writing, such as referencing, as well as on discipline-specific requirements – however, detailed correction of drafts and instruction in aspects of language and style are not the responsibility of the supervisor.
6. Advise the student in the production of a research report, dissertation or thesis - provision should be made for adequate, mutually respectful discussion of the recommendations.
7. Ensure that the student has the opportunity to present work at postgraduate / staff seminars / national / international conferences as appropriate.
8. Assist with the publication of research articles as appropriate.

10. Ensure that the work contains no instances of plagiarism, that all citations are properly referenced, and that the list of references is accurate, complete and consistent.
11. Work in accordance with the criteria of acceptability as supplied by the supervisor.
12. Not place the supervisor under undue pressure to submit work for examination until the supervisor is satisfied that it has reached an acceptable level of quality.

Signed at: Bloemfontein

On this 5<sup>th</sup> day of June 20 17

  
Signature

Ronelle Jansen  
Name of student

1988340327  
Student number

  
Signature

D. M. Reid  
Name of study leader / promoter  
(cross out where not applicable)



# **ADDENDUM B**

PERMISSION TO CONDUCT RESEARCH STUDY GRANTED BY

THE HSREC OF THE UNIVERSITY OF THE FREE STATE

IRB nr DC006240  
REC Reference nr 230408-011  
IORG0005187  
PW/00012784

26 July 2017

MS RONELLE JANSEN  
SCHOOL OF NURSING  
IDALIA LOOTS BUILDING  
UFS

Dear Ms Ronelle Jansen

HSREC 47/2017 (UFS-HSD2017/0349)  
PRINCIPAL INVESTIGATOR: MS RONELLE JANSEN  
SUPERVISOR: DR M REID  
PROJECT TITLE: CONCEPTUALISING A MOBILE HEALTH COMMUNICATION FRAMEWORK FOR SOUTH AFRICAN CAREGIVERS  
OF ADOLESCENTS WITH A MENTAL HEALTH DIAGNOSIS IN A RURAL AREA

1. You are hereby kindly informed that the Health Sciences Research Ethics Committee (HSREC) approved this protocol after all conditions were met at the meeting held on 25 July 2017.
2. The Committee must be informed of any serious adverse event and/or termination of the study.
3. Any amendment, extension or other modifications to the protocol must be submitted to the HSREC for approval.
4. A progress report should be submitted within one year of approval and annually for long term studies.
5. A final report should be submitted at the completion of the study.
6. Kindly use the **HSREC NR** as reference in correspondence to the HSREC Secretariat.
7. The HSREC functions in compliance with, but not limited to, the following documents and guidelines: The SA National Health Act, No. 61 of 2003; Ethics in Health Research: Principles, Structures and Processes (2015); SA GCP(2006); Declaration of Helsinki; The Belmont Report; The US Office of Human Research Protections 45 CFR 461 (for non-exempt research with human participants conducted or supported by the US Department of Health and Human Services- (HHS), 21 CFR 50, 21 CFR 56; CIOMS; ICH GCP E6 Sections 1-4; The International Conference on Harmonization and Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH Tripartite), Guidelines of the SA Medicines Control Council as well as Laws and Regulations with regard to the Control of Medicines, Constitution of the HSREC of the Faculty of Health Sciences.

Yours faithfully



DR SM LE GRANGE  
CHAIR: HEALTH SCIENCES RESEARCH ETHICS COMMITTEE



# **ADDENDUM C**

PERMISSION TO CONDUCT RESEARCH STUDY IN THE FREE  
STATE DEPARTMENT OF HEALTH

(PHASE 1)



health

Department of  
Health  
FREE STATE PROVINCE

01 June 2017

Ms. R.Jansen  
School of Nursing  
Idalia Loots Building  
UFS

Dear Ms. R Jansen

**Subject CONCEPTUALISING A MOBILE HEALTH COMMUNICATION FRAMEWORK FOR SOUTH AFRICAN CAREGIVERS OF ADOLESCENTS WITH A MENTAL HEALTH DIAGNOSIS IN A RURAL AREA.**

- Please ensure that you read the whole document. Permission is hereby granted for the above – mentioned research on the following conditions:
- Participation in the study must be voluntary.
- A written consent by each participants must be obtained
- Serious adverse events to be reported and/or termination of the study.
- Ascertain that your data collection exercise neither interferes with the day to day running of facilities nor the performance of duties by the respondents or health care workers.
- Confidentiality of information will be ensured and please do not obtain information regarding the identity of the participants.
- Research results and a complete report should be made available to the Free State Department of Health on completion of the study (a hard copy plus a soft copy).
- Progress report must be presented not later than one year after approval of the project to the Ethics Committee of University of Free State and to Free State Department of Health.
- Any amendments, extension or other modifications to the protocol or investigators must be submitted to the Ethics Committee of University of Free State and to Free State Department of Health.
- **Conditions stated in your Ethical Approval letter should be adhered to and a final copy of the Ethics Clearance Certificate should be submitted to [sebec@ufshealth.gov.za](mailto:sebec@ufshealth.gov.za) before you commence with the study**
- No financial liability will be placed on the Free State Department of Health
- Please discuss your study with the institution managers/CEOs on commencement for logistical arrangements
- Department of Health to be fully indemnified from any harm that participants and staff experiences in the study
- Researchers will be required to enter in to a formal agreement with the Free State department of health regulating and formalizing the research relationship (document will follow)
- You are encouraged to present your study findings/results at the Free State Provincial health research day
- Future research will only be granted permission if correct procedures are followed see <http://nhrl.hst.org.za>

Trust you find the above in order.

Kind Regards

Dr D Motau

HEAD: HEALTH

Date: 02/06/17

Head : Health  
PC Box 227, Bloemfontein, 9300  
4<sup>th</sup> Floor, Executive Suite, Sphoelo House, on Malandrand Harvey Road, Bloemfontein  
Tel: 051 408 1646 Fax: (051) 408 1648 e-mail: [users@fshealth.gov.za](mailto:users@fshealth.gov.za) [info@fshealth.gov.za](mailto:info@fshealth.gov.za) [hr@fshealth.gov.za](mailto:hr@fshealth.gov.za) [dh@fshealth.gov.za](mailto:dh@fshealth.gov.za)

[www.fs.gov.za](http://www.fs.gov.za)

## **ADDENDUM D**

PERMISSION GRANTED BY THE HSREC TO CHANGE THE TITLE  
OF THE STUDY



Health Sciences Research Ethics Committee

27-Feb-2019

Dear Mrs Ronelle Jansen

Ethics Number: UFS-HSD2017/0349

Ethics Clearance: **An mHealth communication framework for caregivers of adolescents with mental health issues (HSREC47/2017)**

Principal Investigator: Mrs Ronelle Jansen

Department: School of Nursing Department (Bloemfontein Campus)

**SUBSEQUENT SUBMISSION APPROVED**

With reference to your recent submission for ethical clearance from the Health Sciences Research Ethics Committee, I am pleased to inform you on behalf of the HSREC that you have been granted ethical clearance for your request as stipulated below:

Study title amendment from **Conceptualising a Mobile Health Communication Framework for South African Caregivers of Adolescents with a Mental Health Diagnosis in a Rural Area to**

**An mHealth communication framework for caregivers of adolescents with mental health issues.**

The HSREC functions in compliance with, but not limited to, the following documents and guidelines: The SA National Health Act, No. 61 of 2003; Ethics in Health Research: Principles, Structures and Processes (2015); SA GCP(2006); Declaration of Helsinki; The Belmont Report; The US Office of Human Research Protections 45 CFR 461 (for non-exempt research with human participants conducted or supported by the US Department of Health and Human Services- (HHS), 21 CFR 50, 21 CFR 56; CIOMS; ICH-GCP-E6 Sections 1-4; The International Conference on Harmonization and Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH Tripartite), Guidelines of the SA Medicines Control Council as well as Laws and Regulations with regard to the Control of Medicines, Constitution of the HSREC of the Faculty of Health Sciences.

For any questions or concerns, please feel free to contact HSREC Administration: 051-4017794/5 or email [EthicsFHS@ufs.ac.za](mailto:EthicsFHS@ufs.ac.za).

Thank you for submitting this request for ethical clearance and we wish you continued success with your research.

Yours Sincerely

Dr. SM Le Grange

Chair : Health Sciences Research Ethics Committee

Health Sciences Research Ethics Committee

Office of the Dean: Health Sciences

T: +27 (0)51 401 7795/7794 | E: [ethicsfhs@ufs.ac.za](mailto:ethicsfhs@ufs.ac.za)

IRB 00006240; REC 230408-011; IORG0005187; FWA00012784

Block D, Dean's Division, Room D104 | P.O. Box/Posbus 339 (Internal Post Box G40) | Bloemfontein 9300 | South Africa  
[www.ufs.ac.za](http://www.ufs.ac.za)



# **ADDENDUM E**

INFORMATION LEAFLETS AND CONSENT FORMS FOR  
PARTICIPATING IN THE MMOGO-METHOD®  
(PHASE 1)

(English, Afrikaans and Sesotho copies)

## **INFORMATION LEAFLET: PARTICIPATION IN THE GROUP (MMOGO-METHOD®)**

**Study title:** Conceptualising a mobile health communication framework for South African caregivers of adolescents with a mental health diagnosis in a rural area

*Researcher: Mrs Ronelle Jansen*

*Mobile number: 0825544731*

Dear participant

I am a student at the School of Nursing from the University of the Free State. If you look after a young person who has a mental illness, I will ask you, if you want to join a group where we will talk about it. If you come for the group, I will ask you a question about, how cell phones can help you to support the mentally ill young person. You are going to “answer” me by making something with your hands. I will give you the material that you can use to make something. Afterwards everybody will get a turn to show the group what they made. Then you will be asked to talk about all the things that everybody made. I will take a photo of the thing that you made. I will tape the group’s talking with a recorder. The group will be about 2 to 3 hours long. You will only do one group.

You must tell me if you want to do this group or not. I won’t be angry if you don’t want to do this group. You don’t have to pay any money for this group. I don’t think you will get hurt if you do this group. You will not receive any money if you come for the group. I will give you something to eat and pay for transport on the day of the group. I will not use your name if I talk about the groups’ discussion.

I can go to other cities and tell them what happened in the groups or give the story to academic magazines. I will not give your name to these people. I can show them the photos of the things that you made, but I will not tell them who you are.

If you have any questions or problems about the groups, phone me at 0825544731.

If you don’t like something that I do or say, you can phone the following number and just tell them what is bothering you: 051 401 7795.

Yours truly

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Mrs. Ronelle Jansen, Cell: 0825544731, [jansenro@ufs.ac.za](mailto:jansenro@ufs.ac.za)

## **INLIGTINGSTUK: DEELNAME AAN DIE GROEP (MMOGO-METHOD®)**

*Titel: Conceptualising a mobile health communication framework for South African caregivers of adolescents with a mental health diagnosis in a rural area*

Navorser: Mev. Ronelle Jansen

Selfoon nommer:

0825544731

Beste deelnemer

Ek is 'n student by die Skool vir Verpleegkunde aan die Universiteit van die Vrystaat. As jy vir 'n jongmens sorg wat 'n mental siekte het, wil ek jou vra om aan 'n groep deel te neem, sodat ons daarvoor kan praat. As jy vir die groep kom, gaan ek jou vra om iets met jou hande te maak. Ek sal vir julle die materiaal gee, wat jy kan gebruik om iets te maak. Daarna sal almal 'n kans kry om vir die groep te wys wat hulle gemaak het. Julle gaan dan gevra word om almal daarvoor te praat. Ek gaan ook foto's neem van dit wat julle gemaak het. Ek gaan alles opneem wat julle in die groep praat. Die groep sal sowat 2 tot 3 uur lank wees. Jy gaan net een groep doen.

Jy moet vir my sê of jy hierdie groep wil doen of nie. Ek sal nie kwaad wees as jy dit nie wil doen nie. Jy hoef nie enige geld te betaal vir hierdie groep nie. Ek dink nie jy sal seerkry as jy hierdie groep doen nie. Ek gaan nie enige geld vir jou betaal om die groep te doen nie. Ek sal vir jou iets gee om te eet en vir vervoer op die dag van die groep. Jy gaan nie enige presentie kry as jy die groep doen nie. Ek sal nie jou naam gebruik as ek oor die groepe praat nie.

Ek kan na ander dorpe gaan en hulle vertel wat in die groepe gebeur het of ek kan die storie aan akademiese tydskrifte gee. Ek sal nie jou naam vir hierdie mense gee nie. Ek kan hulle die foto's wys van die dinge wat julle gemaak het, maar ek sal nie vir hulle sê wie jy is nie.

As jy enige vrae of probleme het oor die groepe, bel my by 0825544731.

As jy nie hou van enige iets wat ek gesê of gedoen het nie, kan jy die volgende nommer bel en vir hulle daarvan sê: 051 401 7795.

Die uwe

---

Mrs. Ronelle Jansen, Sel: 0825544731, [jansenro@ufs.ac.za](mailto:jansenro@ufs.ac.za)

## PAMPERING YA TSEBISO: HO NKA KAROLO SEHLOPHENG (MMOGO-METHOD®)

**Sehloho Thutho:** Conceptualising a mobile health communication framework for South African caregivers of adolescents with a mental health diagnosis in a rural area

Mobatlisisi: *Mrs Ronelle Jansen*

Mobile number: 0825544731

Ho motho ya tlo nka karolo

Ke morutwana Sekolong sa Booki, sa Universiti ya Foreisitata. Ha ikopanya o hlokomela motho a monyane anang le mathatha a kelello, ke tla o botsa hore ha o na thabela ho ikopanya le rona re bueng ka taba e. E bang o tla ho rona, ke tlo o botsa potso ya hore sel founu e ka o thusa jwang ho tshietsa motho a monyane anang le mathatha a kelello. O tlong araba ka ho etsa ntho e nyane ka matsohò a hao. Ke tla fana ka masela a tla o thusa ho etsa ntho e nyane ka matsohò a hao. Ka mora moo re tla kopa batho kaofeela ba re bontshe ntho e bona ba e entseng ka matsohò a bona. Ebe ha re qetile re tla bua ka dintho tse emong le emong wa lona a di entseng ka matsohò a hae. Ke tla qetella honka senepe sa dintho tse re di entseng ka matsohò a rona. Meqoqo ya rona kopanong tseno e tla bewa ka hara "tape" ke nna. Kopano tsa rona di tla nka hora tse 2 ho isa ho tse 3. O tla nka karolo ho sehlopa sele seng.

O tla ntsebisa ha o batla ho nka karolo ho sehlopa sena. Ha ke na kwata ha o sa batle ho ba karolo ya hlopa sena. Ha ona patala tjelele ho hlopa sena. Ha ke nahane o ka lemala ha ole hlopeng sena. Ha o no thola tjelele ha ole karolo ya hlopa sena. Empa o tla thola dijo, ke tla patala le taxi mohlang re tsamayang re le sehlopa. Ha ke na sebedisa lebitso la hao ha ke qoqa ka ditaba tsa hlopha sa rona.

Empa nka kgona ho ya tropong tse ding ka ba qoqela hore na ho ne ho etsahala eng ka hara hlopha sa rona, kapa ka fana ka taba tsa hlopha sena ho ba ngodi ba di buka. Ke kopa o tsebe hore ha hona mohlang ke tla fana ka bitso la hao ho batho bana. Ke tla ba bontsha feela dintho tseo o di entseng ka matshoho a hao, mara eseng ke fane ka lebitso la hao.

Ha o na le di potso kapa mathatha mabapi le hlopa se, o ka nfonela ho 0825544731.

Ha o sa rate ntho e ke buang kapa e ke etsang, o ka letsetsa 051 401 7795. Wa ba jwetsa hore ke eng e sa o tswarang handle.

Wa hao ya ratehang

---

Mrs. Ronelle Jansen, Cell: 0825544731, [jansenro@ufs.ac.za](mailto:jansenro@ufs.ac.za)



## INGELIGTE TOESTEMMING: DEELNAME AAN DIE GROEP (MMOGO-METHOD®)

Jy is gevra om 'n groep te doen in \_\_\_\_\_ (Dorp)

Mev. Ronelle Jansen het vir jou vertel waarom die groep gaan. Sy het genoem dat sy met vervoer sal help asook iets om te eet as jy vir die groep gaan kom. As jou hart seer word wanneer jy in die groep praat, sal sy reël dat jy hulp daarvoor kry.

Jy kan mev. Ronelle Jansen, enige tyd bel as jy vrae of probleme oor die groep het, by 0825544731. As die groepe jou hartseer gemaak het, kan jy haar ook bel.

Jy kan die volgende nommer, 051 401 7795, by die Universiteit van die Vrystaat bel, indien jy enige vrae het oor iets wat ek, mev. Jansen, gesê of gedoen het in die groep waarvan jy nie hou nie.

Jy kan kies of jy die groep wil doen of nie. Jy kan enige tyd stop as jy dit nie meer wil doen nie. Jy sal nie seergemaak of gestraf word as jy dit nie wil doen nie.

As jy besluit om die groep te doen, sal jy 'n getekende afskrif van hierdie dokument kry, asook die inligtingstuk.

Mev Jansen het vir my alles oor die groeeproses gesê. Ek verstaan wat om in die groep te doen en ek gee my toestemming om die groep te doen.

\_\_\_\_\_  
Handtekening van deelnemer

\_\_\_\_\_  
Datum

\_\_\_\_\_  
Handtekening van getuie  
(Waar van toepassing)

\_\_\_\_\_  
Datum

\_\_\_\_\_  
Handtekening van interpreteerder  
(Waar van toepassing)

\_\_\_\_\_  
Datum

## TUMELO FOROMO: HO NKA KAROLO SEHLOPHENG (MMOGO-METHOD®)

O kopilwe ho etsa sehlopha \_\_\_\_\_ . (Toropo)

O se o jwetsitse hore sehlopha sena ke sa eng ke Mme Ronelle Jansen. O jwetsitse hore o tla o thusa ka tjehelete ya taxi le dijo ha o nka karolo ho se hlopha sena. E bang utlwa bohloko ke meqoqo e ka hara sehlopha, o tla o batlela motho a tla bua le wena.

O ka founela Mme Ronelle Jansen Ho 082 554 4731 nakong engwe le engwe ha ona le kapa mathatha mabapi le sehlopha.

O ka letsetsa 051 401 7795, Universiti ya Foreisitata ha o na le di potso mabapi le ntho e Mme Jansen a e buileng kapa a entseng o sa e rateng.

O ka nka karolo ha o batla. O ka emisa nako engwe le engwe ha o sa batle ho tswela Pele. Ha ono fuwa kotlo kapa wa utlwiswa bohloko ha o sa batle ho nka karolo.

Ha o dumela ho nka karolo sehlopheng se, o tla fuwa pamperi/tokomane ena e tsamaya le Pamperi ya di tsebiso.

Mme Jansen o njwetsitse tsohle ka sehlopha sena. Ke ya utlwisisa hore karolo yaka ke efeng ka hara sehlopha hape ke fana ka tumello yaka ya hoba karolo ya sehlopha.

_____	_____
Motekeno wa Monkakarolo	Letsatsi
_____	_____
Motekeno wa Paki	Letsatsi
(moo ho hlokehang)	
_____	_____
Motekeno wa Toloko	Letsatsi
(moo ho hlokehang)	

# **ADDENDUM F**

SYSTEMATIC REVIEW CRITICAL APPRAISAL:

TWO SENIOR RESEARCHERS' REFERENCES

PHASE 2

**Researcher 1:**

*Dr Deirdre E. van Jaarsveldt* obtained an MSocSc in Psychiatric Nursing and a PhD in Higher Education Studies from the University of the Free State (UFS). She is currently the Head: Research Portfolio at the School of Nursing, UFS. Dr van Jaarsveldt has been in the employment of the UFS since 1999 and has extensive experience in psychiatric nursing, child psychiatric nursing, learning and teaching, as well as research. The focus of her research and publications is on diversity and inclusivity in higher education

**Researcher 2:**

*Dr. Cynthia Spies* obtained the BSocSc degree in Nursing at the University of the Free State (UFS) in 1993. She obtained a Diploma in Child Health Nursing in 1995 at the Free State School of Nursing. She joined the School of Nursing at UFS as a part-time lecturer in 1996. Apart from part-time work at the School of Nursing, she worked as a professional nurse in children's wards and the paediatric intensive care unit in the Universitas Academic Hospital in Bloemfontein. She obtained the Advanced University Diploma in Nursing Education in 2008 and MSoc Sc (Nursing) in 2010 at UFS. In 2011 she commenced a full time academic career at UFS and works as a lecturer who specializes in paediatric nursing and nursing education with a particular interest in high-fidelity simulation as a teaching and learning method. She obtained her PhD in Nursing in 2016.

# **ADDENDUM G**

SYSTEMATIC REVIEW: DATA EXTRACTION

PHASE 2

Data extraction:

Population: caregivers.

Intervention: mHealth & eHealth.

Outcomes: IMBP

RCT					
Bibliographic detail	Methodology	Outcomes & Intervention	Critical appraisal	Study findings	Grading & Hierarchy
<p>1. A randomized trial of teen online problem solving: Efficacy in improving caregiver outcomes after brain injury. Wade, Shari L.; Walz, Nicolay C.; Carey, JoAnne; McMullen, Kendra M.; Cass, Jennifer; Mark, Erin; Yeates, Keith Owen; Health Psychology, Vol 31(6), Nov, 2012 pp. 767-776. Publisher: American Psychological Association.</p>	<p><b>Aim:</b> To examine the results of a randomized clinical trial (RCT) of Teen Online Problem Solving (TOPS), an online problem solving therapy model, in increasing problem-solving skills and decreasing depressive symptoms and global distress for caregivers of adolescents with traumatic brain injury (TBI).</p> <p><b>Design:</b> Randomized control trial</p> <p><b>Setting:</b> The trauma registries and the inpatient rehabilitation units of two urban children's hospitals</p> <p><b>Sample:</b> A total of 137 children were identified as potentially eligible. We successfully contacted 121 of these families regarding their participation.</p>	<p><b>Hypothesis:</b> We hypothesized that parents of adolescents in the TOPS group would report greater reductions in depression and distress and greater improvements in problem solving than those in the IRC.</p> <p><b>Secondary hypothesis:</b> We further hypothesized that socioeconomic status would moderate treatment effects with families of lower SES showing greater improvements following TOPS.</p> <p><b>Third hypothesis:</b> Finally, we tested the hypothesis that reductions in depression and global distress were mediated by improvements in problem solving.</p> <p><b>Data collection:</b> Caregivers in both groups completed a satisfaction survey and those receiving TOPS completed a companion</p>	<p><b>Tool used: CASP tool for RCT:</b> The trial addressed a clear focused issue (population, intervention, comparator, outcomes)</p> <ul style="list-style-type: none"> <li>Families were randomly assigned to either TOPS or IRC using a randomization scheme that stratified participants based on sex and race/ethnicity. This was done to ensure that the groups were equivalent with respect to these characteristics.</li> </ul> <p>Both participants and research staff were aware of group assignment.</p> <p>Participants in the TOPS and IRC groups did not differ significantly with respect to demographic characteristics such as age or SES nor did they differ on measures of parent problem solving, depression, or psychological distress at pre-treatment.</p>	<p>The results provide evidence that TOPS was well received by parents and may contribute to improvements in parental problem solving, depression, and distress, particularly among those of lower SES. Although a trend was found for greater reductions in global distress in the TOPS versus IRC group, this difference did not achieve statistical significance. However, SES moderated the effects of TOPS on rational problem solving, positive problem orientation, and depressive symptoms, with parents of lower SES who received TOPS reporting significant improvement from baseline to follow-up on each of these measures, whereas parents of lower SES in the IRC group did not report improvements. Interestingly, parents of higher SES in the IRC treatment also reported significant increases in their positive problem orientation and concomitant reductions in depression, whereas those of higher SES in TOPS failed to report improvements on these</p>	<p>10/11 A</p>

	<p>Forty-one (n=41) consented and completed baseline assessments. TOPS/20, IRC/21.</p> <p><b>Inclusion criteria:</b> Eligibility criteria included age at enrolment between 11 and 18 years and hospitalization for a moderate to severe traumatic brain injury (TBI) in the previous 18 months</p> <p><b>Exclusion criteria:</b> Adolescents were excluded if the primary language spoken in the home was not English; there was documentation of child abuse as a cause of the injury and the perpetrator remained in the home; or if the teen or primary caregiver had a psychiatric hospitalization prior to the injury.</p>	<p>questionnaire regarding ease of use and helpfulness of specific aspects of the TOPS Web site (Web site Evaluation Questionnaire; WEQ),</p> <p><b>Intervention group:</b> The TOPS intervention involved an initial home visit by the therapist and 9–13 subsequent web-based sessions. The content for each session was covered in two separate parts: in the first part, the teen, primary caregiver, and other participating family members completed a self-guided module that could be accessed at a password-protected Web site; and then, in the second part, participating family members reviewed the Web site content with the therapist during a synchronous videoconference. Caregivers in both groups completed a satisfaction survey, and those receiving TOPS completed a companion questionnaire regarding ease of use and helpfulness of specific aspects of the TOPS Web site. Participants in the TOPS group had an average of 10 synchronous meeting with the therapist and</p>	<p>Both treatments were presented as active and potentially helpful treatments.</p> <p>Record of participants regarding completion or discontinuation.</p> <p>Both qualitative and quantitative methods were used to assess the caregiver’s experience with the TOPS and IRC websites, associated technology, and intervention content. T tests and chi square analyses or Fisher’s exact tests were conducted to compare the TOPS and IRC groups on continuous and dichotomous background and injury characteristics, respectively.</p> <p>Similar analyses were conducted to examine baseline differences between those who completed the study and those who dropped out.</p> <p>Overall group differences were examined using analysis of covariance, in which the baseline score on the measure of interest served as a covariate thereby allowing us to assess</p>	<p>measures. Thus, the findings provide some evidence that while TOPS may be effective in reducing depression among parents of lower SES, IRC may be as effective for parents of higher SES.</p> <p><b>Caregiver satisfaction:</b> Respondents in the TOPS group rated the program as significantly more helpful overall as well as more helpful in working with their child than did respondents in the IRC group. Additionally, TOPS participants rated the program as more enjoyable than IRC participants. Nearly all participants in both groups endorsed increased knowledge regarding TBI, but significantly higher proportions of TOPS participants endorsed understanding their child better and feeling less stressed.</p> <p><b>Improvements in problem solving:</b> Post hoc analyses indicated that only parents of lower income in the TOPS group reported significant improvements in rational problem solving from baseline to follow-up. For the positive problem orientation subscale, post hoc t test analyses revealed that parents of lower income in TOPS group and parents</p>	
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		<p>each meeting involved approximately 1 hour of direct contact and 1 hour of scheduling and charting.</p> <p><b>Control group:</b> Families in the IRC group also received high-speed Internet access and a computer and printer if they did not currently have them. Additionally, IRC families received access to a home page of brain injury resources and links to online resources but were not able to access specific session content. Families were encouraged to spend at least an hour each week accessing information regarding pediatric brain injury on the Web throughout the 6-month intervention period. At follow-up, parents provided information about the Web sites visited and the time spent at each site.</p> <p>Follow-up assessments were completed 7.83 months following baseline in the TOPS group and 7.92 months following baseline in the IRC group.</p> <p>To address disparities in Internet</p>	<p>change over time.</p>	<p>of higher income in the IRC group both reported significant improvements from baseline to follow-up.</p> <p><b>Improvements in depression and global distress:</b> Post hoc analyses revealed that parents of lower SES in the TOPS group reported significant reductions in depressive symptoms from baseline to follow-up, as did parents of higher SES in the IRC group. SES did not moderate treatment effects on the SCL-90, nor did the groups differ on the SCL-90 at follow-up after controlling for baseline scores, <math>F(1, 32) = 3.05, p = .09</math>, [(TOPS <math>M = 48.85 (SE = 1.98)</math> vs. IRC <math>M = 54.03 (SE = 2.16)</math>].</p> <p><b>Limitations:</b> The study is limited by the relatively small and heterogeneous sample. The study design also precluded distinguishing improvements due to the specific elements of the treatment (i.e., training in problem solving) from those arising from supportive involvement with a skilled therapist. Assessment of problem solving skills and parent distress relied solely on self report, and thus improvements may have been</p>	
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		<p>access and utilization, all participating families were provided with high speed Internet access through the project, when available. Additionally, any family without an existing home computer was given one to use for the duration the study.</p>		<p>inflated by social desirability biases. Additionally, utilization data were not collected from the IRC group thus precluding comparison of the groups with respect to time spent on the intervention.</p> <p><b>Recommendations:</b>          Future studies would benefit from extended follow-up and objective measures of parent <b>problem solving skills</b> and depressive symptoms and global distress. Larger studies employing multifactorial designs would enable researchers to evaluate the relative importance of the therapist's involvement as well as the added value of the additional content on anger management, communication, and social skills, beyond that of standard problem-solving therapy.</p>	
<p>2. A web-based mental health program: Reaching parents at work. Deitz, Diane K.; Cook, Royer F.; Billings, Douglas W.; Hendrickson, April; Journal of Pediatric Psychology, Vol 34(5), Jun, 2009 Special Issue: eHealth in Pediatric</p>	<p><b>Aim:</b>          To test a web-based program providing <b>working parents</b> with <b>the knowledge and skills</b> necessary for prevention and early intervention of mental health problems in youth.</p> <p><b>Design:</b> Randomized controlled trial with pre test-</p>	<p><b>Hypothesis:</b>          We hypothesized that compared to the control group, parents receiving <b>the web-based</b> program would exhibit significant gains in important outcomes, including (a) <b>knowledge</b> of mental health issues in youth; (b) <b>self-efficacy</b> in handling mental health issues in youth; (c) better family</p>	<ol style="list-style-type: none"> <li>1. Tool used: CASP tool of RCT</li> <li>2. Clear design and focus.</li> <li>3. Parents or primary caregivers of elementary, middle, and high school youth were randomly assigned to either an experimental group that received access to the YMH Web site or a waitlist control</li> </ol>	<p>The <b>total knowledge</b> score was significantly greater for the experimental group than for the control group, as were the scores for the <b>knowledge</b> subscales of anxiety, depression, and treatment options. Paired t-test analysis of pretest to posttest differences in the experimental group indicated that mean scores rose in the expected direction for all subscales</p>	<p>9/11 A</p>

<p>Psychology. pp. 488-494.  Publisher: Oxford University Press</p>	<p>post-test comparisons in each group.</p> <p><b>Setting:</b> Workplace of parents (?) ISA associates.</p> <p><b>Sample:</b> The 99 participants in our study were recruited from a worksite with a pool of 350 employees who were caregivers of youth between the ages 5 and 21 (size of the pool estimated by the company's wellness director).</p> <p><b>Inclusion criteria:</b> Participants were required to have a child currently living at home but were not required to have a child currently experiencing a mental health difficulty.</p> <p><b>Exclusion criteria:</b> Not stated.</p>	<p>cohesion, adaptability, and <b>positive</b> communication; and (d) more <b>positive attitudes</b> toward seeking mental health services.</p> <p><b>Data collection:</b> Pre-test and post-test surveys. Different scales to measure</p> <p><b>Intervention:</b> Parents or primary caregivers of elementary, middle, and high school youth were randomly assigned to either an experimental group that received access to the YMH <b>Web site</b> or a waitlist control group. The intervention period was for 2 weeks, and participants in the experimental group were encouraged to view the program as often as possible within that time period. After the pretest and review period, all participants (experimental and control conditions) were asked to complete the post-test survey. The <b>web-based YMH program</b> consists of four modules that are multimedia rich, fully narrated, and interactive. The use of a <b>multimedia approach</b> (as opposed to the usual "click and read" programs) was</p>	<p>group.</p> <ol style="list-style-type: none"> <li>4. Can't tell if it was blinded.</li> <li>5. The experimental and control groups did not differ significantly in chi-square analysis on any of the demographic characteristics of interest.</li> <li>6. Not clear if treated equally.</li> <li>7. Ninety-nine employees enrolled in the program, resulting in a participation rate of 28% of the company-estimated pool of potential participants. The response rates were similar for the intervention (96%) and control groups (98%). There were no significant differences between the groups on the measures of family communication, adaptability, cohesion, and attitudes toward mental health issues. The total knowledge score was significantly greater for the experimental group than for the control group, as were the scores for the knowledge subscales of anxiety, depression, and treatment options. There was a significant difference between</li> </ol>	<p>and were statistically significant for knowledge of treatment (<math>t = -2.92, p = .006</math>) and total <b>knowledge</b> (<math>t = -7.96, p = .000</math>). These analyses did not reach significance for <b>knowledge</b> of anxiety, depression, and parenting. Paired t-test analysis of pre-test to post-test differences in the control group were non-significant for all measures except total <b>knowledge</b> (<math>t = -6.69, p = .000</math>). There were no significant differences between the groups on the measures of family communication, adaptability, cohesion, and <b>attitudes</b> toward mental health issues. There was a significant difference between the experimental and control groups on <b>self-efficacy</b> in handling mental health issues in their children (<math>F = 12.73, p = .001</math>). Also significant was the paired t-test analysis of increases in self-efficacy from pre-test to post-test among the individuals receiving the intervention (<math>t = -3.20, p = .003</math>). The study results demonstrate that parents receiving a <b>web-based intervention</b> had significantly greater knowledge of children's mental health issues and greater <b>self-efficacy</b> in handling these issues compared to waitlist controls. These findings indicate that</p>
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		<p>designed to make the program more appealing and engaging, while providing opportunities for behavioral modelling and raising <b>self-efficacy</b>, with the intent of leading users to adopt new <b>attitudes, beliefs, and behaviors</b></p> <p><b>Experimental group:</b> Experimental group participants were asked to rate the web-based program content on dimensions of clarity, usefulness, appeal, and ability to motivate.</p> <p><b>Control group:</b> Waitlist control</p>	<p>the experimental and control groups on self-efficacy in handling mental health issues in their children. Sub analyses investigating dosage of intervention, differences between families with known or suspected mental health problems, and reactions to the program were also conducted, but were not significant, and are not reported in this brief.</p> <p>8. ANCOVAs analysis used. 9. Can be applied. 10. Needs clear. 11. Benefits are worthwhile.</p>	<p>the YMH program can be an effective intervention for improving parents' <b>knowledge</b> of children's mental health problems and boost their confidence in handling such issues. No significant effects of the intervention were found in family cohesion, adaptability, communication, and <b>attitudes</b> toward mental health and help-seeking.</p> <p><b>Limitations:</b>First, a potential concern with any <b>web-based</b> intervention is the "dose" or level at which participants completed their review of the program. We could not adequately control for individuals who simply skimmed through the program or those who had minimal interest in the program content. Another limitation relates to the lack of external validity—the extent to which the findings are generalizable to other, more diverse workforces and populations—as all participants were white and relatively well educated and the majority did not have a known or suspected mental health concern with their child(ren). Finally, the cafeteria-based recruitment procedure probably led to some selection bias in the sample.</p> <p><b>Recommendations:</b> Web-based programs can also be</p>	
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				<p>offered to individuals in multiple settings, including the workplace and at home, thereby reaching large numbers of parents. As <b>use of the Internet</b> continues to grow in the general population and in multiple settings such as the workplace, these kinds of programs hold promise for reaching large numbers of parents who are concerned with their children's mental health. Future research could compare the added value of <b>web-based interventions</b> to traditional clinical intervention.</p>	
Bibliographic detail	Methodology	Outcomes & Intervention	Critical appraisal	Study findings	Grading & Hierarchy
<p>3. Acceptability and feasibility of an e-mental health intervention for parents of childhood cancer survivors: "Cascade". By: Wakefield, Claire; Sansom-Daly, Ursula; McGill, Brittany; Ellis, Sarah; Doolan, Emma; Robertson, Eden; Mathur, Sanaa; Cohn, Richard; Wakefield, Claire E; Sansom-Daly, Ursula M; McGill, Brittany C; Ellis, Sarah J; Doolan,</p>	<p><b>Aim:</b> This study aimed to pilot a group-based, e-health, cognitive behavioral intervention to support <b>parents</b> of children recovering from cancer.</p> <p><b>Design:</b> RCT</p> <p><b>Setting:</b> Sydney Children's Hospital, Australia</p> <p><b>Sample:</b> Parents n=56 Intervention n=25 Complete n=24</p>	<p><b>Outcomes:</b> The study examined the feasibility (aim 1) , acceptability (aim 2), and safety and psychological impact (aim 3) of Cascade. <i>Question 1 and aim 1, Question 2 and aim 2</i></p> <p><b>Question 3:</b> Was Cascade associated with any changes in parents' quality of life (QoL, the primary outcome), depression, anxiety, fear of recurrence, or family functioning (secondary</p>	<p><b>Tool used: CASP tool RCT</b></p> <ol style="list-style-type: none"> <li>1. Clear design and focus.</li> <li>2. Independent personnel at Sydney Children's Hospital used an electronic randomizer to allocate participants to Cascade or the waitlist.</li> <li>3. It was not possible for the psychologists, the research officer, and the participants to be blinded. However, the statistician remained blinded until all analyses were completed. There were no significant</li> </ol>	<p><b>Aim 1 (feasibility):</b> Most participants (n = 41, 91.1 %) had Internet access and the necessary technical equipment (e.g., web camera and microphone). The structure of Cascade appeared feasible: 40 % of parents (n = 12) indicated that the existing three weekly, 2-h, sessions were appropriate, with 11 parents (37 %) indicating that they would value more sessions. Fidelity data revealed good adherence to the intervention manual. The psychologists reported a technical difficulty in most sessions (n =17,</p>	<p>10/11 A</p>

<p>Emma L; Robertson, Eden G; Cohn, Richard J. Supportive Care in Cancer. Jun2016, Vol. 24 Issue 6, p2685-2694</p>	<p>Waitlist n=22</p> <p><b>Inclusion criteria:</b> Parents were eligible if they (i) had a child aged 15 years or younger who had completed cancer treatment with curative intent in the past 5 years, (ii) were able to read English, and (iii) were able to access the Internet in a private location</p> <p><b>Exclusion criteria:</b> Parents were excluded if, during the interview, they (i) had insufficient English skills; (ii) were experiencing extreme anxiety or depression (reflected in extremely severe scores on the Depression, Anxiety, Stress Scales-Short Form and endorsed serious suicidal intent; (iii) endorsed current symptoms of psychosis or substance abuse; or (iv) had a child who was on active treatment, had relapsed, or was in palliative care.</p>	<p>outcomes)? Different scales and questionnaires used.</p> <p><b>Data collection:</b> Parents completed questionnaires at baseline (T1), 2 weeks (T2), and 6 months (T3) after participation in Cascade. Waitlist controls were assessed during the waitlist period (T2/T3), and following their participation in Cascade (T4).</p> <p><b>Intervention group:</b> The manualized program consists of three, weekly, 120-min <b>online sessions delivered through WebEx</b> (Cisco WebEx, USA). Cascade is a synchronous <b>e-mental health intervention</b> as it is delivered B-live by a psychologist in real time. Two psychologists specifically trained in the delivery of Cascade were involved in the running of the program. WebEx is a password-<b>protected video-conferencing program</b> that allows up to six participants to be seen on the screen simultaneously, much like group Skype™. Cascade groups comprised a psychologist plus three to five parents. The</p>	<p>demographic or cancer treatment differences between parents randomized to Cascade or to the waitlist. However, Cascade parents were more likely to reside in a regional/ remote area.</p> <p>4. After 6 months, waitlisted parents were invited to participate in Cascade. Parents completed questionnaires at baseline (T1), 2 weeks (T2), and 6 months (T3) after participation in Cascade. Waitlist controls were assessed during the waitlist period (T2/T3), and following their participation in Cascade (T4).</p> <p>5. The number of parents who dropped out of the study was equally distributed across groups. In line with recommend-dations for pilot studies [35], the target sample size was 40 participants (i.e., ~20 in each group, with a 1:1 allocation ratio). The trial was stopped when this sample was reached. Analysed according to groups.</p> <p>6. See findings aim 1 &amp; 2 effect</p>	<p>80.9 %),</p> <p><b>Aim 2 (acceptability):</b> YSQ data indicated that parents were very satisfied with Cascade and that it met their needs. Most participants positively evaluated Cascade's <b>online</b> format, <b>skills-focused content</b>, and the peer-group setting. Most parents indicated that Cascade was “quite” or “very” beneficial (n =19, 70 %). Qualitatively, parents noted that Cascade was a significant time commitment (n= 6), but that its benefits outweighed the time “cost” (n = 5/6). Parents appreciated Cascade as a “nonthreatening” and “honest” <b>forum that provided a context for reflection and processing</b> (e.g., “helped consolidate my <b>thoughts and feelings</b>”) and fostered “the realisation that you are not alone”. Overall, they rated the level of peer-to-peer conversation, rapport within the group, participant openness, and mutual trust between participants, most highly.</p> <p><b>Aim 3 (safety &amp; psychological):</b> Participants appeared to be coping well overall: at baseline, few showed severe symptoms of depression (n =0), anxiety (n =1), or stress (n =6).</p>	
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		<p>same parents attended the same group for all three sessions, led by the same psychologist. After each session, the psychologist sent participants an email with purposely designed home practice activities.</p> <p><b>Control group:</b> After 6 months, waitlisted parents were invited to participate in Cascade.</p>	<p>reported. Despite the encouraging feasibility and acceptability data, no significant results emerged to indicate that the program improved parents' QoL or reduced distress.</p> <ol style="list-style-type: none"> <li>7. Descriptive analysis used. It was significant.</li> <li>8. It can be applied.</li> <li>9. Need described</li> <li>10. Benefits worth harms and costs.</li> </ol>	<p>There was no significant main effect of group (i.e., waitlist vs. intervention) or time (i.e., baseline vs. post-intervention vs. followup) on quality of life, psychological functioning, and family functioning.</p> <p><b>Conclusion:</b> Cascade appears to be feasible and highly acceptable, and its efficacy is worthy of further evaluation. Good evidence emerged for Cascade's feasibility (aim 1). Good opt-in and attrition rates reflect a population that was receptive to psychological support. Parents indicated that the session structure was practicable, with many satisfied with the number of intervention sessions, or requesting more. A strength of this study was its inclusion of parent and psychologist perspectives. Data from both perspectives demonstrated that Cascade was highly acceptable (aim 2). Consistent with psychologist impressions, almost all parents were highly satisfied with the skills taught during Cascade and indicated that its benefits outweighed the "burdens". Despite the encouraging feasibility and acceptability data, no significant results emerged to</p>	
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				<p>indicate that the program improved parents' QoL or reduced distress.</p> <p><b>Limitations:</b>  The small sample size was a key limitation and precluded our capacity to detect any intervention effects. Apart from the small sample, there are several additional reasons why the program may not have yielded significant effects. Parents may not have received an adequate "dose" of the intervention across the three sessions. Also, the current sample was not clinically distressed and represented parents who had already had up to 5 years to adjust to their child's survivorship. Further, while participants resided in many parts of the state of New South Wales, the hospital's catchment area has residents of a higher than average socioeconomic status relative to other areas. Additional limitations include the lack of external fidelity checks and the absence of an attention control group. The study had a low representation of fathers.</p> <p><b>Recommendations:</b>  It is critical that future studies better engage this under-supported (fathers) group. The development of</p>	
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				future online interventions targeting not only this group but also parents of children affected by other serious illnesses. A four module (plus booster) program is likely to be acceptable, given that many parents requested additional sessions.	
Bibliographic detail	Methodology	Outcomes & Intervention	Critical appraisal	Study findings	Grading & Hierarchy
4. Can mobile phone multimedia messages and text messages improve clinic attendance for Aboriginal children with chronic otitis media? A randomised controlled trial. Phillips, James H.; Wigger, Christine; Beissbarth, Jemima; McCallum, Gabrielle B.; Leach, Amanda; Morris, Peter S.; Journal of Paediatrics and Child Health, Vol 50(5), May, 2014 pp. 362-367. Publisher: Wiley-Blackwell Publishing Ltd	<p><b>Aim:</b> Does phone multimedia messages (MMS) to families of Indigenous children with tympanic membrane perforation (TMP): (i) increase clinic attendance; (ii) improve ear health; and (iii) provide a culturally appropriate method of health promotion?</p> <p><b>Design:</b> RCT</p> <p><b>Setting:</b> Two remote Northern territory Indigenous communities, Australia.</p> <p><b>Sample:</b> Fifty-three (n=53) Australian Aboriginal children with a TMP living in remote</p>	<p><b>Primary outcome:</b> The primary outcome of this study was measured as the number of clinic appointments attended, for any reason, during the 6-week intervention period by each child. Attendance was determined by accessing the community clinic's electronic primary care information system.</p> <p><b>Secondary outcome:</b> The secondary outcomes were (i) ear health state at the end of the study period (healed tympanic membrane, presence of ear discharge, reduced perforation size); and (ii) participant satisfaction with text messages and MMS, assessed by face-to-face structured interviews using standardised questionnaires.</p>	<p><b>Tool used:</b> CASP tool RCT</p> <ol style="list-style-type: none"> <li>Clearly stated population, intervention, comparator and outcomes.</li> <li>Yes, it was randomized. We used Stata Version 11.1 for participant randomisation. The randomisation sequence was stratified by age and community, with a 1:1 allocation</li> <li>Assessors were blinded to the intervention allocations.</li> <li>Yes. See inclusion criteria.</li> <li>(Can't tell) but: YES However, both groups received two stand-alone text messages in English, one at the start acknowledging their participation in the study and one at the end asking them to attend the clinic for the</li> </ol>	<p><b>Primary outcome:</b> The mean number of clinic visits per child for any reason was 1.3 (95% confidence interval (CI) 0.6, 2.1) for the control group and 1.3 (95% CI 0.6, 1.9) for the intervention group (Table 1a). There was no statistically significant difference between these two groups (mean difference -0.1, 95% CI -1.1, 0.9; P = 0.9). The total number of clinic visits for any reason in the intervention group was 1.5 (95% CI 0.5, 2.5). The mean difference of 0.2 (95% CI -1.0, 1.4) between the two groups remained statistically non-significant (P = 0.7).</p> <p><b>Secondary outcome:</b> One child in the control group and three children in the intervention group had healed perforations. These differences were not significant (risk difference 6%, 95%</p>	9/11 = 11/11? A

	<p>community households with a mobile phone were randomised into intervention (n = 30) and control (n = 23) groups. For both groups, 28 (57%) respondents were primary carers (mostly the child's mother or grandmother) who owned the phone, 11 (23%) were primary carers (mostly child's mother or grandmother) who did not own the phone and 10 (20%) respondents were the nominated household relatives who owned the phone (child's father, aunt or older sibling). Assessors were blinded to the intervention allocations. To reduce observer variation, a second blinded assessor reviewed all the video recordings. Any perforation size difference of &gt;10% between the primary examiner and second blinded assessor were reviewed by a third assessor. If there was any persistent disagreement, the assessment was based on the initial examiner's</p>	<p><b>Data collection:</b> Assessed by face-to-face structured interviews using standardised questionnaires. The end of study questionnaire included a mixture of dichotomous, open-ended and multiple choice questions such as 'Did you see any phone messages from the Menzies Ear Health Team?' and 'Would you be happy to receive other health related videos in the future?'</p> <p><b>Intervention group:</b> Eligible participants were randomised into two groups: intervention and control. The primary carers (or someone else in the household with a mobile phone) in the intervention group were sent seven ear health MMS in the local Indigenous language, one every 4 days, with a window of <math>\pm 24</math> h. The MMS were accompanied by personalised ear health text messages in English that included a prompt to visit the clinic for the children's health check-ups. Follow-up for questionnaire (n = 30) Follow-up for clinical outcomes (n = 28)</p>	<p>final assessment. Both groups received an information sheet with local clinical treatment guidelines and advice to attend the clinic weekly for review. Experimental intervention was different.</p> <p>6. Yes. They were accounted for. See p. 364 + 365.</p> <p>7. Yes. This pilot RCT did not identify significant differences in the attendance rates or ear health outcomes resulting from regular MMS messaging. These findings suggest attendance rates for severe otitis media in this population are very low when compared with the recommended weekly clinic review. We were able to confirm the acceptability of mobile phone-based interventions to promote health outcomes in these settings.</p> <p>8. Yes.</p> <p>9. It can be applied.</p> <p>10. Yes. All outcomes considered.</p> <p>11. Worthy.</p>	<p>CI -10, 20; P = 0.6). Around 70% in each group still had CSOM (risk difference -1%, 95% CI -30, 30; P = 1.0) and 20-25% of children had a DP. In the control group, the average baseline perforation size in the worst ear was 20% (95% CI 10, 30). At follow-up, it was unchanged at 20% (95% CI 11, 30). The average perforation size in the intervention group had increased from 20% (95% CI 15, 25) of the total eardrum at baseline to 25% (95% CI 15, 35). The mean difference in perforation size in the worst ear at follow-up between the two groups was 3% (95% CI -11, 17) and was non-significant (P = 0.7).</p> <p><b>Participants' views:</b> Thirty-seven (76%) of all participants at follow-up said they were happy to receive health messages in the future (Table 4). Sixteen of the 19 (84%) families in the control (95% CI 60, 90) and 21/30 (70%) families in the intervention group (95% CI 50, 80) reported that they were happy to receive text or MMS health-related messages in the future. The risk difference of -14% (95% CI -37, 8) was not statistically different (P = 0.3). Nine (17%) participants</p>	
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	<p>findings.</p> <p><b>Inclusion criteria:</b> Participants had to satisfy each of the following eligibility requirements: (i) be an Indigenous child aged 13 years or under; (ii) have an acute or chronic TMP; (iii) live in one of the two remote communities long term; and (iv) have a parent/carer or other family member living in the same household with a working mobile phone who was willing to receive the messages.</p> <p><b>Exclusion criteria:</b> Not found</p>	<p><b>Control group:</b> The control group received no MMS and accompanying text messages. Follow-up for questionnaire (n = 19) Follow-up for clinical outcomes (n = 19).</p> <p>However, <b>both groups</b> received two stand-alone text messages in English, one at the start acknowledging their participation in the study and one at the end asking them to attend the clinic for the final assessment. Both groups received an information sheet with local clinical treatment guidelines and advice to attend the clinic weekly for review</p>		<p>presented to the clinic on the day they received this text message. Three participants said that they would prefer simple text messages with a specific appointment time rather than MMS health messages.</p> <p>We received signed informed consent for 181 children. Fifty three (30%) children were able to be randomised (Fig. 1). The control group had 23 participants and the intervention group had 30. Clinic attendance was determined for all 53 children. Forty seven (89%) children had a follow-up ear examination and 49 (92%) participant families completed a follow-up interview. At follow-up, we interviewed 19 (83%) participants from the control group and 30 (100%) participants from the intervention group. For both groups, 28 (57%) respondents were primary carers (mostly the child's mother or grandmother) who owned the phone, 11 (23%) were primary carers (mostly child's mother or grandmother) who did not own the phone and 10 (20%) respondents were the nominated household relatives who owned the phone (child's father, aunt or older sibling). Eight (29%) primary carers (who</p>	
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				<p>owned the phone) and six (55%) primary carers (who did not own the phone) reported that they did not see any of the messages. In the intervention group, 10 (33%) respondents reported not seeing any of the messages. Of these, two had broken phones, one phone number had been incorrectly transcribed, four said a relative had the phone, and one reported that the messages did not work. We received no explanation from the remaining two participants.</p> <p><b>Limitations:</b>  This pilot study was not able to recruit the desired sample size of 90 participants. One factor that contributed to this was unrest and fighting in one of the communities before and during the study, which restricted our time to contact and enrol families. Long waiting times at the local clinics can be a disincentive, and we were also not able to assess if participants did present to the clinic but did not wait to be seen. Taking into account our finding that the primary carer of the child was less likely to see the phone messages if other family members within the household owned the phone, it is probable that</p>	
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				<p>this type of intervention would be more effective if the primary carer owned the phone.</p> <p><b>Recommendations:</b> It is possible that short, simple <b>text messages</b> with appointment times or treatment at home reminders would be more effective in encouraging short-term behaviour change. Alternatively, a study conducted over a longer time period would potentially be more effective.</p>	
Bibliographic detail	Methodology	Outcomes & Intervention	Critical appraisal	Study findings	Grading & Hierarchy
<p>5. <b>Counselor-assisted</b> problem solving improves caregiver efficacy following adolescent brain injury. Wade, Shari L.; Karver, Christine L.; Taylor, H. Gerry; Cassedy, Amy; Stancin, Terry; Kirkwood, Michael W.; Brown, Tanya Maines; Rehabilitation Psychology, Vol 59(1), Feb, 2014 pp. 1-9. Publisher: American Psychological Association</p>	<p><b>Aim:</b> The purpose of the current study is to examine the efficacy of Counselor-Assisted Problem Solving (CAPS) in improving <b>caregiver</b> adaptation following traumatic brain injury (TBI).</p> <p><b>Design:</b> RCT</p> <p><b>Setting:</b> Registries of five major trauma-centers in the Central and Western regions of the United States.</p> <p><b>Sample:</b></p>	<p><b>Primary outcome:</b> We hypothesized that CAPS would result in greater reductions in parent depression and distress and greater increases in caregiving efficacy than would access to Internet resources alone.</p> <p><b>Secondary outcome:</b> Moreover, we extended consideration of potential moderators by evaluating the influences of race/ethnicity as well as factors considered in previous studies (computer usage, SES) on treatment response.</p>	<p><b>Tool used:</b> CAPS tool RCT</p> <ol style="list-style-type: none"> <li>1. Yes. Clear focused population, intervention, comparator and hypothesis.</li> <li>2. To ensure that group composition was balanced with respect to both gender and within each of the sites, randomization was stratified on these factors.</li> <li>3. A SAS program was created using permuted block sizes for each of the randomizations. A sealed envelope containing group assignment was handed to the participants at the end of</li> </ol>	<p>Both CAPS and IRC were associated with significant reductions in caregiver distress, however, CAPS was not more effective than IRC in this regard. However, results from the current study indicate that adults who are infrequent technology-users may experience greater increases in caregiver efficacy if their experience with technology is scaffolded by therapist support and guidance. Interestingly, in the IRC group, without such support, parents who were not frequent computer users reported declines in caregiving efficacy despite the fact that they accessed information about brain</p>	<p>11/11 A</p>

	<p>Randomized (n=132) CAPS (n=65) IRC (n=67)</p> <p><b>Inclusion criteria:</b> Children between the ages of 12–17 years who were hospitalized overnight for a complicated mild to severe TBI within the previous 1–6 months were considered for inclusion. Additional eligibility requirements included documented alteration of neurological functioning as measured by either a Glasgow Coma Scale (GCS) score less than 13 and/or evidence of neurological insult as seen on MRI or computerized tomography, English as the primary language spoken in the home, availability of the adolescent to participate in the intervention, and family residence within a 3 hr drive of the hospital.</p> <p><b>Exclusion criteria:</b> included: (a) insufficient child recovery by 6 months post injury to participate in the intervention (e.g.,</p>	<p><b>Data collection:</b> Background questionnaire and baseline interview</p> <p><b>Intervention group:</b> Adolescents and their families were randomly assigned to either of two 6-month long <b>Internet-based interventions:</b> CAPS, described in greater detail below, a family problem-solving intervention that provided training in communication skills, self-regulation and anger management. The intervention was designed to be completed over a 6-month period with weekly sessions for the first 2–3 weeks and then biweekly sessions until the family completed the initial seven core sessions.</p> <p><b>Control group:</b> An Internet resource comparison (IRC) group, a self-guided, information-based program. Families in the IRC group also received computers and Web cameras, the latter was provided to keep the interviewers unaware of group assignment. Families were encouraged to spend at</p>	<p>the baseline visit allowing interviewers to remain naïve to group assignment at the baseline assessment. Thus, interviewers/research assistants were unaware of group assignment at both assessments, whereas parents were naïve to group assignment only at the baseline visit.</p> <p>The groups were well matched with respect to demographic and injury characteristics with no significant differences between groups noted. To ensure that group composition was balanced with respect to both gender and within each of the sites, randomization was stratified on these factors. CAPS, described in greater detail below, a family problem-solving intervention that provided training in communication skills, self-regulation and anger management; or an Internet resource comparison (IRC) group, a self-guided, information-based program.</p> <p>4. They were all accounted for.</p>	<p>injury. In explaining this finding, it may be that when noncomputer users are offered computer access without the support and scaffolding provided by the therapist to use the technology, general feelings of <b>self-efficacy</b> and confidence may decrease, including caregiving efficacy. Thus, the present results yield a more nuanced understanding of the potential role of prior technology experience in treatment efficacy. Contrary to earlier studies, the findings suggest that parents with limited prior computer experience may be equally or more likely to benefit from therapist-guided, Web-based interventions. Associations between demographic factors and self-report measures of distress and <b>caregiving efficacy</b> using point biserial correlations were also non-significant, with coefficients ranging from .01 between CES-D and race, to .10 between CSES and race. Significant moderate to large correlations were observed among measures of caregiver distress ( <math>r = .37</math> between CSES and GSI, <math>r = .38</math> between CSES and CES-D, and <math>r = .67</math> between GSI and CES-D). For the trimmed intent to treat regression models for the CES-D, all individual factors (income, race/</p>	
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	<p>persistent significant cognitive or verbal impairments that would prevent participation in the intervention, such as inadequate verbal and communication skills or insufficient attentional capabilities); (b) psychiatric hospitalization for either child or parent during the year prior to the injury; (c) family residence in an area without high-speed Internet access; (d) child residence outside the home (e.g., detention facility) or (e) diagnosis of intellectual disability (IQ 65) prior to the injury.</p>	<p>least 1 hr per week accessing information regarding paediatric brain injury on the Web throughout the 6-month intervention period and to track the sites that they visited.</p>	<p>Trial did not stop early.  5. See findings.  6. Yes. Some significance  7. Families who may be candidates for Web-based interventions, such as those living in rural areas, may be expected to benefit from Web-based interventions that offer support for technology use.</p>	<p>ethnicity, and computer use) were eliminated due to non-significance. Results revealed a trend for greater improvements in the CAPS versus IRC group (<math>p = .055</math>). Follow-up analyses removing participants who completed fewer than four sessions of CAPS revealed a significant effect for group, <math>F(1, 110) = 4.79, p = .03</math>. Although the <math>R^2</math> change was small (.03), mean differences at follow-up, CAPS = 9.90 (8.36) versus IRC = 15.46 (11.75) indicated medium sized effects (Cohen's <math>d = .52</math>). See Table 2. For the trimmed regression models for the SCL-90 GSI score, all individual factors were again eliminated due to non-significance. Results revealed no significant differences between groups at follow-up in either the intent-to-treat or more restricted analyses after controlling for baseline (preintervention) scores. Post hoc analyses indicated comparable, and statistically significant, reductions in global distress in both the CAPS and IRC group (<math>M</math> CAPS = 3.29; <math>M</math> IRC = 3.64; <math>p = .007</math> for both analyses), suggesting that both treatment conditions were associated with reductions in caregiver distress. Follow-up analyses revealed that,</p>	
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				<p>among nonfrequent computer users, CAPS parents reported significantly higher levels of caregiver efficacy than did IRC parents at the 6-month follow-up, <math>F(41) = 7.15, p = .01</math>. See Figures 2a and 2b. The corresponding effect size was moderate (Cohen's <math>d = .51</math>). Conversely, among frequent computer users, there were no group differences in caregiver self-efficacy at follow-up, <math>F(74) = .05, p = .82</math>, and neither CAPS nor IRC evidenced changes in CSES scores from baseline to the 6-month follow-up. Contrary to expectations and prior research, caregiver education and race/ethnicity did not moderate treatment response on any of the parent outcomes assessed. Additionally, prior computer use did not moderate the efficacy of CAPS in reducing caregiver depression and distress. a significant interaction was found between group and computer use when considering CSES as the dependent measure, controlling for group and baseline CSES scores (<math>F = 5.62, t = 1.96, p = .05</math>).</p> <p>Parents who were non-frequent computer users again evidenced higher self-efficacy than did those in the IRC. Also similar to the intent to</p>	
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				<p>treat analyses, caregiver education and race/ethnicity did not moderate treatment response on any of the parent outcomes assessed and prior computer use did not moderate the efficacy of CAPS in reducing caregiver depression and distress.</p> <p><b>Limitations:</b>  The groups were well-matched on most demographic, injury, and baseline characteristics; however, relatively low levels of distress on the SCL-90 GSI in CAPS group at baseline may have created floor effects. Additionally, although the treatment conditions were equated for access to reliable information and resources regarding TBI, including <b>Web sites</b> regarding problem-solving strategies and stress management, the groups were not equated for therapist attention. Therefore, although we can tentatively conclude that CAPS is superior to access to <b>Internet</b> resources alone in reducing caregiver depressive symptomatology following TBI, we cannot conclude that it is superior to other forms of treatment affording therapist support. Reliance on self-report measures of parent outcomes is a further limitation. Additionally, as</p>	
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				<p>reported in Figure 1, a large proportion (57.1%) of potential participants that were assessed for eligibility were either deemed ineligible or declined to participate, potentially limiting generalizability of the current findings. The exclusionary criteria that the family residence must be in an area with high-speed Internet access may result in families living in rural areas being underrepresented and the criteria that English must be the primary language spoken in the home potentially results in exclusion of members of diverse populations. Specifically, potential participants that decline participation were more likely to be non-White and have sustained less severe injuries than participants. It is also notable that the median family income of the obtained sample is above the national median despite substantial variability in income levels. These limitations in recruitment and generalizability should be considered when interpreting the current results. Additionally, although the intent-to-treat model suggested that greater sessions completed was associated with greater improvements in caregiver depression, it is notable that the</p>	
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				<p>presence of a subset of participants that did not complete the entire course of treatment likely reduced the strength of the study's design and limited our ability to detect improvements in caregiver outcomes that result following the CAPS intervention. Finally, the approach to assessing treatment fidelity to the CAPS intervention may be vulnerable to bias on the part of the therapist and untrained caregivers may be unable to make reliable evaluations about treatment fidelity. Future studies may wish to use other methods for assessing treatment fidelity, such as an expert independent rater.</p> <p><b>Recommendations:</b> None stated.</p>	
Quasi experiential					
Bibliographic detail	Methodology	Outcomes & Intervention	Critical appraisal	Study findings	Grading & Hierarchy
<p>6. Development and preliminary evaluation of culturally specific web-based intervention for parents of adolescents. By: Choi, H.; Kim, S.; Ko, H.; Kim, Y.; Park, C. G. Journal of Psychiatric &amp;</p>	<p><b>Aim:</b> To assess the feasibility of developing and implementing a culturally specific <b>web-based intervention</b> for Korean <b>parents</b>, by assessing recruitment, retention, acceptability, and variation</p>	<p><b>Outcomes:</b> intended to increase <b>parental knowledge</b>, parental <b>self-efficacy</b>, parent-child communication, and satisfaction with parent-child relationships, and to decrease parent-child conflicts, parental stress, and child-based worth.</p>	<p><b>Tool used:</b> Joanna Briggs checklist for Quasi-Experimental studies.</p> <ol style="list-style-type: none"> <li>1. Yes</li> <li>2. Schools with similar sizes and profiles (e.g., students' socioeconomic status,</li> </ol>	<p><b>Outcomes acceptability:</b> Overall, parents were satisfied with the content of the Stepping Stone program (M = 3.50, SD = .04), and gave high ratings for the length (M = 3.73, SD = .06), ease of use (M = 3.75, SD = .06), and practicality/ applicability of the program (M =</p>	<p>9/9 = 100% ?C</p>

<p>Mental Health Nursing. Oct2016, Vol. 23 Issue 8, p489-501. 13p.</p> <p>?? Stepping stones program rather than web?</p>	<p>in outcome variables, which will inform a larger study.</p> <p><b>Design:</b> A two-group, repeated measures, quasi-experimental study.</p> <p><b>Setting:</b> Two elementary schools and four middle schools from four cities in Korea.</p> <p><b>Sample:</b> Using cluster and convenience sampling strategies. N= 214 recruited. 131/intervention and 83/AC groups (baseline survey) Received intervention-60, AC – 54. Analysed intervention-47, analysed AC-46.</p> <p><b>Selection:</b> Upon receiving approval from the principals of selected schools, we recruited participants through parent orientation meetings and letter invitations. We provided detailed information about the study and web-based intervention for parents.</p>	<p><b>Data collection:</b> Questionnaires. Phone and individual interviews.</p> <p><b>Intervention group:</b> Parents assigned to the intervention group participated in the 4-week Stepping Stone program, whereas those assigned to the AC group received a healthy diet intervention for 4 weeks. Parents assigned to the AC group were later invited to complete the Stepping Stone program, after they had completed the 1-month follow-up survey.</p> <p><b>Control group:</b> The attention control (AC) group received the same amount and duration of education as the experimental group. Participants in the AC group also experienced the same study procedure, including recruitment and data collection procedure, to control for the effects of the therapeutic relationship between researchers and participants.</p> <p><b>Results:</b> Despite the random assignment</p>	<p>standardized test scores, neighbourhood characteristics) were selected, and then randomly assigned to either the intervention (one elementary and two middle schools, plus half of the online community participants) or AC (one elementary and two middle schools, plus half of the online community participants) groups. The attention control (AC) group received the same amount and duration of education as the experimental group. Participants in the AC group also experienced the same study procedure, including recruitment and data collection procedure, to control for the effects of the therapeutic relationship between researchers and participants.</p> <p>3. Yes 4. Yes, different scales used. Besides watching the media files, parents were asked to complete 15-min questionnaires before beginning the first session (baseline), at the end of the fourth session (posttest), and 1 month after the post-test (1-</p>	<p>3.65, SD = .08), although they gave low ratings for its novelty (M = 2.99, SD = .20). Among the four sessions, parents were most satisfied with the fourth session, which addressed various strategies promoting parent-child relationships and presented success stories shared by mothers. Regarding the specific strengths of the intervention, parents reported that it provided time for self-reflection and helped them understand their child's perspective, and they found the information about mental health services useful. Regarding the intervention's shortcomings, parents reported that the content on mental health issues was not specific enough for those who were currently struggling with child's mental health problems, and they requested the inclusion of more practical parenting skills that were applicable to daily parent-child interactions. At baseline, there were no significant differences in demographic characteristics or outcome variables between the intervention and AC groups. After completing the 4-week Stepping Stone program, participants in the intervention, compared to AC, group demonstrated preliminary evidence</p>	
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	<p>including the purposes, expected commitment from participants, and detailed procedure. Interested parents were asked to submit an application to their child's teacher or to contact the research team members. We then contacted via phone or email each parent who applied, again provided information about the study, and answered any questions.</p> <p><b>Inclusion criteria:</b> The target population was parents of adolescents aged 11 to 16 years old, who were residing in Korea. Parents who met the following inclusion criteria were invited to participate: (1) had at least one child aged 11 to 16 years old; (2) were currently living with the child; and (3) were able to understand Korean</p> <p><b>Exclusion criteria:</b> Not stated.</p>	<p>strategy we used, group sizes varied because of differences in the response rates. We were able to recruit parents from diverse areas of the country with relatively low cost. There were 114 parents (60 and 54 in the intervention and AC groups, respectively) who completed all four sessions of the program; however, only 47 from the intervention group and 46 from the AC group completed the 1-month follow-up survey.</p>	<p>month follow-up) to measure changes in the study variables.</p> <ol style="list-style-type: none"> <li>5. Yes, adequately described.</li> <li>6. Yes.</li> <li>7. Yes. To analyse the interview data, two research team members independently coded the transcripts and identified themes that appeared repeatedly. We then classified the data into three parts: strengths of the programs, limitations of the program or barriers to participation or remaining in the program and areas for improvement.</li> <li>8. The data were analysed with IBM SPSS version 21.0 and STATA 14 (StataCorp 2015).</li> </ol> <p><b>Benefits:</b> The program could be used to deliver interventions for parents across diverse settings, including schools and community mental health centers, if the intervention effect is determined via a larger trial. we believe that the benefits of web-based interventions could be maximized when disseminated in collaboration</p>	<p>of improved parental knowledge. Further, there were group differences in the level of knowledge sustained 4 weeks after the post-test.</p> <p>Parents in the intervention group also showed increased parental self-efficacy, parent-child communication, and satisfaction with parent-child relationships, and decreased parent-child conflict, parental stress, and child-based worth (see Table 4). The gaps between the two groups were particularly large at the 1-month follow-up for parent-child communication, parent-child conflict, satisfaction with parent-child relationships, and parental stress. Only the effect size of parental knowledge was large (<math>d = 0.60</math>; 95% CI: 0.21–0.99); that of the other outcome variables was very small, ranging from 0.01 (95% CI: <math>-.030</math> to 0.32, parental self-efficacy) to 0.13 (95% CI: <math>-.018</math> to 0.43, satisfaction with parent-child relationships). The completers were more educated (<math>P \leq .001</math>) and had a higher level of parental knowledge (<math>P = .004</math>). Specifically, we demonstrated that one of very few culturally specific web-based interventions for Korean parents</p>	
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			<p>with health services, education systems, and/or existing community networks</p>	<p>addressing adolescents' mental health is feasible, and identified areas and issues to consider when implementing similar interventions. Parents who completed the program found it to be accessible, easy to understand, and appropriate for disseminating general information to large numbers of parents. In addition, the change in parental <b>knowledge</b> of adolescents' development and mental health in the desired direction was observed.</p> <p><b>Limitations:</b>          Limitations of the study include non-equivalent sample sizes between the intervention and AC groups, which may have caused selection bias and generalizability issues. We monitored how many times each participant visited the study <b>website</b> and the amount of time they spent on each session, and added a function to prevent them from proceeding without completing each session. However, we were still not able to differentiate between participants who engaged fully, compared to shallowly, with the program content. Considering the low retention rate observed in this study, further studies are needed to examine the impact of high dropout</p>	
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				<p>rates and the dose–response relationship in relation to <b>web-based intervention</b>. These factors might be one of the reasons for the inconsistent results that have been obtained regarding the effects of <b>intervention programs involving technology</b>. Another limitation to this study is the small sample size, particularly for non-random samples.</p> <p><b>Recommendations:</b>  this study also recommended recruiting participants based on existing therapeutic relationships between the researchers (or service providers) and parents. She also recommended utilizing <b>web-based interventions</b> as an educational tool in conjunction with self-help groups for parents. Besides using regular reminders, utilizing online communities and a social network approach is recommended for future <b>web-based programs</b>, in order to increase recruitment and retention rates.</p>	
Bibliographic detail	Methodology	Outcomes & Intervention	Critical appraisal	Study findings	Grading & Hierarchy
7. A pilot study using electronic communication in home healthcare:	<b>Aim:</b> The aim of the study was to explore the impact	<b>Outcomes:</b> The purpose of this study was to explore the utility of a nurse-	Joanna Briggs Institute (JBI) for quasi-experimental stool: 1. Yes.	Pre- and post-intervention <b>well-being</b> cumulative scores did not significantly differ ( $z = -1.207, p <$	5/5 ?C

<p>implications on parental wellbeing and satisfaction caring for medically fragile children. Haney T, Tufts KA. Home Healthc Nurse. 2012;30:216–24.</p>	<p>that this form of communication would have on <b>parent's self-reported well-being and satisfaction</b> and to produce preliminary findings to the value of conducting future research on the use of an e-mail communication program to enhance <b>caregiver</b> well-being and satisfaction.</p> <p><b>Method:</b> Quasi-experimental one-group pre- and post-intervention pilot study.</p> <p><b>Setting:</b> In a small pediatric home healthcare agency located in a major metropolitan city in the south-eastern United States. This agency provides care to 46 families of children with multiple medical conditions.</p> <p><b>Sample:</b> Purposive sampling took place. A total of 19 participants were enrolled. Mean parental age was 36 with a range of 23 to 53 years. The ill child's mean</p>	<p>established and nurse-managed <b>electronic communication</b> on the impact of self-reported well-being and satisfaction of parents of medically fragile and technologically dependent children cared for at home.</p> <p><b>Research questions:</b> <i>RQ1: Do parents of medically fragile and technologically dependent children cared for at home report improved well-being following the implementation of a nurse-established and nurse-managed <b>electronic communication</b>?</i> <i>RQ2: Do parents of medically fragile and technologically dependent children cared for at home report improved satisfaction following the implementation of a nurse-established and nurse-managed <b>electronic communication</b>?</i></p> <p><b>Data collection:</b> Questionnaires.</p> <p><b>Intervention:</b> Following enrollment the 12-week <b>structured electronic communication intervention</b> began simultaneously for all</p>	<ol style="list-style-type: none"> <li>2. N.a. – no comparison</li> <li>3. N.a</li> <li>4. N.a</li> <li>5. Yes. Frequencies and measures of central tendency were used to describe the sample. The PedsQL™ Family Impact and Satisfaction tools were selected to measure outcomes on parental self-reported <b>well-being and satisfaction</b>. Both instruments have established reliability; PedsQL™ Family Impact Module (<math>\alpha = 0.97</math>) and PedsQL™ Satisfaction Module (<math>\alpha = 0.90</math>).</li> <li>6. <b>All 19 parents</b> completed the post intervention instruments and returned them via the postal mail. See procedure.</li> <li>7. N.a. no comparison group.</li> <li>8. Yes. Nr 5.</li> <li>9. Yes. Wilcoxin <i>T</i> tests were used to assess differences in pre- and post-intervention parental self-reported <b>well-being and satisfaction</b></li> </ol>	<p>.227). There was also no significant difference between pre- and post-<b>parent well-being</b> subset scores (<math>z = -1.006, p &lt; .314</math>) and family well-being subset scores (<math>z = -1.348, p &lt; .178</math>). Satisfaction scores also did not differ between pre- and post-intervention satisfaction scores (<math>z = -.631, p &lt; .528</math>). Although the study findings do not reflect significant quantitative differences in parental self reported well-being or satisfaction, there was a 9-point increase in <b>parental satisfaction</b>. This study demonstrates the potential benefits of communicating, <b>supporting, educating,</b> and guiding families via electronic communication. Exploration into the benefits of different forms of electronic communication warrants further research. In conclusion, the home care nurse cannot change the unpredictable nature of parenting a medically fragile child. The nurse may, however, be able to provide ongoing support and education via different forms of <b>electronic communication</b>. Therefore, contributing to improved <b>parent well-being and satisfaction</b>.</p>	
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	<p>age was 9.17 years with a range of 4 months to 23 years.</p> <p><b>Inclusion criteria:</b> Inclusion criteria for study participation included (a) the ability to read and write in English and (b) access to the Internet either in the form of e-mail or text messaging. Recruitment took place over a 2-month period.</p> <p><b>Exclusion criteria:</b> Not found.</p>	<p>parents. The first e-mail sent to parents outlined the guidelines for online communication. Parents were reminded that e-mail communication was not to be used for emergency purposes. Over 12-weeks healthcare education or parenting topics related to caring for a chronically ill child at home were sent from the nurse to the parent's identified e-mail address at the start of each week. IRB-approved topics were preselected prior to the start of the study. While the weekly topics were standardized the e-mails were personalized to each parent to encourage communication and rapport with the nurse. Parents were encouraged to e-mail questions, comments, and concerns to the nurse. The nurse responded asynchronously to the parent e-mails within 24 to 48 hours Monday through Friday.</p> <p><b>Procedure:</b> Pre-intervention data were collected from each parent at the time of enrolment, this included sociodemographic information,</p>		<p><b>Limitations:</b> Lessons Learned and Limitations</p> <ul style="list-style-type: none"> <li>• Recruitment was difficult because of the busy nature of parenting a chronically ill child.</li> <li>• Invitation letters did not prove to be an effective method. Phone calls may have proved to be more effective.</li> <li>• Early buy-in from the visiting nurse may have increased enrolment.</li> <li>• Pediatrics is a small segment of home care, to achieve adequate sample size additional agencies may need to be used.</li> <li>• The intervention should take place over a longer timeframe (6 months to 1 year). This would allow time for the parent to develop a level of comfort with the nurse. This may also adjust for negative life events that may occur over the course of the study.</li> <li>• Parents wanted to express themselves despite the forms being quantitatively based. Future research should include opportunities to collect data that is qualitative in nature.</li> </ul>	
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		parental self-reported well-being, and parental self-reported satisfaction. The intervention was then implemented over a 12-week period. Two weeks before the conclusion of the study, parents were reminded through e-mail that they would be mailed follow-up questionnaires. During the last week of the study parents were mailed the follow up PedsQL™ Family Impact and PedsQL™ Satisfaction questionnaires along with a self-addressed and stamped envelope to the nurse. <b>All 19 parents</b> completed the post intervention instruments and returned them via the postal mail.			
Qualitative articles					
Bibliographic detail	Methodology	Outcomes & Intervention	Critical appraisal	Study findings	Grading & Hierarchy
8. Clinic Personnel, Facilitator, and Parent Perspectives of eHealth Familias Unidas in Primary Care. Molleda, L., Bahamon, M., St. George, S.M., Perrino, T, Estrada, Y., Herrera, D.C., Pantin, H. & Prado,	<b>Purpose:</b> The purpose of this descriptive qualitative study was to examine the feasibility and acceptability of implementing eHealth Familias Unidas in pediatric primary care settings from the perspectives of all those	<b>Data collection:</b> <b>In-depth interviews:</b> 9 semi-structured, face-to-face interviews with physicians, a nurse practitioner, clinic administrators, and facilitators. Conducted a focus group with parents at	<b>Note each step:</b> 1. The purpose clearly stated. 2. Qualitative methodology appropriate. 3. Research design appropriate. 4. Recruitment strategy appropriate to purpose. 5. Data collected addressed the research issue.	<b>Findings:</b> Nine themes (six from individual interviews and three from focus group). Separate table provided with substantiating quotations. 1. Establish the relevance of the intervention to the setting and population. 2. Engage clinical personnel.	D 9/10

<p>G. 2017</p> <p>Check background for detail of the programme</p>	<p>involved in the pilot study (i.e., clinic personnel, facilitators, and parents). The objectives were to (a) determine the acceptability of delivering <b>Familias Unidas via the Internet??</b>, (b) identify potential barriers and facilitators to family recruitment and intervention implementation in the primary care clinics, (c) collect recommendations on how to overcome barriers and capitalize on strengths of implementation, and (d) elicit suggestions related to sustainability of the intervention in primary care.</p> <p><b>Design:</b> Descriptive qualitative study</p> <p><b>Setting:</b> Individual interviews with clinic personnel and facilitators – one of the two pediatric primary care clinics or the university medical campus; Focus group with parents – university medical campus</p> <p><b>Sample:</b> Purposive sampling</p>	<p>the university medical campus.</p> <p><b>Focus group:</b> Example questions included: How was your decision to participate influenced by the health care setting where you receive health care services? and <b>Can you please describe your experiences in the intervention?</b> The focus group lasted 73 minutes and was audio recorded and transcribed verbatim by a research assistant. Adapted semi structured interview guide; field notes.</p> <p><b>Data analysis:</b> General inductive approach First author – Read all transcripts; created 2 initial codebooks; upper level categories derived from study objectives and lower-level directly from participants responses Second author – Reviewed transcripts and codebooks before coding Both authors – independently coded transcripts, discussed changes and codes, reached</p>	<ol style="list-style-type: none"> <li>6. Relationship between researcher and participants implicitly and partially stated.</li> <li>7. Ethical issues were considered.</li> <li>8. Data analysis was sufficiently rigorous.</li> <li>9. Findings clearly stated.</li> <li>10. Value of the research well motivated.</li> </ol>	<ol style="list-style-type: none"> <li>3. Minimize disruption to clinic flow.</li> <li>4. Improve collaboration and training of clinic personnel and the research team.</li> <li>5. Secure administrative support and funding.</li> <li>6. Provide intervention participants and facilitators with technical and clinical support.</li> <li>7. Promote the clinic as a trusted setting for improving children's behavioral Health.</li> <li>8. Communicate the perceived benefits of the intervention.</li> <li>9. Highlight the flexibility and convenience of eHealth format.</li> </ol> <p><b>Recommendations:</b> include (a) establishing the relevance of the intervention, (b) engaging clinic personnel, (c) minimizing disruption to clinic flow, (d) improving collaboration and training of clinic personnel and research team, (e) securing administrative support and funding, (f) providing intervention facilitators and participants with technical and clinical support, (g) promoting the clinic as a trusted setting, (h) communicating intervention benefits, and (i) highlighting the</p>	
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	<p><b>Inclusion criteria:</b> From two pediatric primary care clinics involved in the eHealth Familias Unidas pilot study</p> <p><b>Exclusion criteria:</b> Third clinic was not included in the qualitative study, because the third clinic's cohort had not yet begun</p>	<p>consensus on discrepant ratings and organise commonly endorsed themes; organised by code into Excel tables; frequency of themes indicated saturation. Consistency ratings were calculated. External reviewers checked accuracy.</p> <p>The strategies and recommendations put forth from the participants are an indication that not only is it possible to integrate and implement an eHealth intervention in a primary care setting, but it is also acceptable and needed.</p>		<p>flexibility of the eHealth format. For the intervention itself, it is imperative that the actual delivery of the intervention complements the clinic's ongoing duties and engages the families. Thus, the convenience of the eHealth format, which streamlines intervention delivery to occur outside the clinic, is a selling point, not only for the clinic, but also for the parents who prefer high flexibility and accessibility of the intervention.</p> <p>Recommendations for the Familias Unidas team; practical considerations and concrete steps for researchers. Future research to consider integration and intersection of quantitative and qualitative data collection and analysis to maximise efficiency of intervention implementation and dissemination in primary care, particularly as it affects patient outcomes.</p> <p><b>Limitations:</b> Small number of participants due to small population; involvement of project coordinator as a researcher who conducted individual interviews and led analysis.</p>	
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Bibliographic detail	Methodology	Outcomes & Intervention	Critical appraisal	Study findings	Grading & Hierarchy
<p>9. eHealth Familias Unidas: Pilot Study of an Internet Adaptation of an Evidence-Based Family Intervention to Reduce Drug Use and Sexual Risk Behaviors Among Hispanic Adolescents. Estrada, Y., Molleda, L., Murray, A., Drumhiller, K., Tapia, M., Sardinias, K., Rosen, A., Pantin, H., Perrino, T., Sutton, M., Cano, M.A., Dorcius, D., Muhamad, J.W. &amp; Prado, G. 2017</p>	<p><b>Purpose:</b> To describe the Internet adaptation of an evidenced-based intervention for Hispanic families, eHealth Familias Unidas, and explore whether an Internet-based format is feasible and acceptable to Hispanic families.</p> <p><b>Design:</b> Qualitative study with quantitative component – session completion rates.</p> <p><b>Setting:</b> Multiple middle schools relatively close to where the families lived and at the University of Miami offices.</p> <p><b>Sample:</b> Purposive sampling – 29 parents.</p> <p><b>Inclusion criteria:</b> Parents who had received the eHealth intervention.</p> <p><b>Exclusion criteria:</b> Not mentioned.</p>	<p><b>Data collection:</b> <b>Focus groups/ interviews:</b> 8 Focus groups and 6 individual interviews with 29 parents. <i>Overall question:</i> Is an internet adaptation of the Familias Unidas intervention, eHealth Familias Unidas, feasible and acceptable to Hispanic families? <i>Probing questions:</i> “What aspects/things in this session did you find you can use and that could be helpful or were not helpful?”, “What were some of your reactions to the telenovela?”, and “Are there things you would change that would make the intervention more appealing to you?” Additional questions related to technological issues parents may have experienced, comments on the interactive exercises, and whether weekly reminders from the facilitators to watch the sessions were reasonable.</p>	<p><b>Note each step:</b></p> <ol style="list-style-type: none"> <li>1. The purpose clearly stated.</li> <li>2. Qualitative methodology appropriate.</li> <li>3. Research design appropriate.</li> <li>4. Recruitment strategy appropriate to purpose.</li> <li>5. Data collected addressed the research issue.</li> <li>6. Relationship between researcher and participants not specified.</li> <li>7. Ethical issues were considered.</li> <li>8. Data analysis was sufficiently rigorous.</li> <li>9. Findings clearly stated.</li> <li>10. Value of the research well motivated.</li> </ol>	<p><b>Findings:</b> Two general themes:</p> <ul style="list-style-type: none"> <li>• Parents provided positive feedback regarding the e-Parent Group Sessions.</li> <li>• Lessons learned as a result of being a part of the intervention, i.e. (1) effective parent-adolescent communication; (2) active parental attention and involvement in adolescent’s life; (3) importance of friends; and (4) importance of communication about sex.</li> </ul> <p><b>Recommendations:</b> Modifications were made to the e-parent group sessions based on the participant feedback.</p> <p><b>Limitations:</b></p> <ol style="list-style-type: none"> <li>1. Given that this a feasibility and acceptability study, it is not possible to make any conclusions regarding the efficacy of the eHealth Familias Unidas intervention. Currently, there is an ongoing randomized trial with eHealth Familias Unidas that will determine whether the intervention has an impact on family functioning, as</li> </ol>	<p>D 9/10</p>

		<p><i>Duration:</i> 30-90 minutes</p> <p><i>Data capturing:</i> Audiorecorded and transcribed. Transcripts uploaded into NVivo and structural codes were applied to the data to label each focus group guide question and participants' responses.</p> <p><b>Data analysis:</b> Two qualitative data analysts thoroughly read each transcript and by structural code to create an emergent data-driven code list. They then discussed any discrepancies and created a preliminary content codebook. To ensure coding consistency, analysts independently coded two transcripts and assessed inter-coder agreement using Kappa scores. Codes with a Kappa score less than 0.80 were reviewed and discussed until consensus was reached. Text segments were recoded and the codebook was finalized. Each analyst then coded six of the remaining twelve transcripts. Salient and co-occurring concepts were</p>		<p>well as youth health risk behaviors.</p> <ol style="list-style-type: none"> <li>2. Sample for this study from a single geographic area, Miami-Dade County – not representative of Hispanics in the United States.</li> <li>3. An inherent self-selection bias with participants who decide to participate in the focus groups; Further, a selection bias also exists with our eligibility criteria, which required families to have Internet access, therefore, potentially excluding families from low socioeconomic status. However, this eligibility criterion was necessary to ascertain that families would be able to access the intervention.</li> </ol>	
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		identified and organized into thematic categories.			
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# **ADDENDUM H**

INFORMATION LEAFLET FOR PARTICIPATING IN THE VALIDATION  
WORKSHOP

PHASE 3

## INFORMATION LEAFLET: VALIDATION WORKSHOP PARTICIPANT

**Study title:** An mHealth communication framework for caregivers of adolescents with mental health issues (HSREC nr. UFS-HSD2017/0349)

*Researcher: Mrs. Ronelle Jansen*

*Mobile number: 0825544731*

I, Ronelle Jansen, am doing research on the development of an mHealth communication framework for caregivers of adolescent with mental health issues in a rural area in South Africa. This research is towards my PhD. A multiple method design will be implemented and a three-phased approach will be followed.

In phase 1, the researcher conducted the Mmogo-method® in two towns from the Kopanong Municipality, Xhariep District in the Free State province. The researcher used purposive sampling of caregivers of adolescents with mental health issues in Trompsburg and Springfontein. Phase 2 was a systematic review. During this phase, the researcher looked at relevant literature for evidence-based articles about strengthening of positive behaviour for caregivers of adolescents with mental health issues using mHealth communication interventions.

This research sought to understand how an mHealth framework could be used by rural South African caregivers of adolescents who have mental health issues. Such a framework may strengthen the caregiver's behaviour in a more positive way when caring for the adolescent with a mental health issue. The researcher used the data of phase 1 and 2 to develop a draft mHealth communication framework.

Phase 3 consists of a research workshop that will validate the draft framework. This workshop will form part of the process to enhance the integrity of the development of a mHealth communication framework. The study promotor, an expert in the Theory of Change Logic model as part of a Complex intervention, will facilitate the validation workshop. You are invited to form part of this workshop as a valuable member with certain expertise.

There are no unforeseeable risks being involved in the study. There are no direct benefits of you being in the study. Your participation is voluntary and you may discontinue participation at any time without penalty or loss of benefits. There are no costs involved in the participation of this study. All efforts will be made to keep personal information confidential. Absolute confidentiality cannot be guaranteed because of the group discussions. Results of the research will be published but no personal information will appear on any document. Organisations that may inspect and/or copy the research records for quality assurance and data analysis include the Health Sciences Research Ethics Committee (HSREC). I will be happy to answer any queries regarding this study and look forward to your participation.

Yours truly \_\_\_\_\_

Mrs. Ronelle Jansen

Cell: 0825544731

[jansenro@ufs.ac.za](mailto:jansenro@ufs.ac.za)

## INFORMED CONSENT:      VALIDATION WORKSHOP PARTICIPANT

You have been asked to participate in a research study.

Mrs Ronelle Jansen has informed you about the study. You have been informed about any available compensation or counselling if emotional harm occurs as a result of study-related procedures;

You may contact **Mrs Ronelle Jansen** at **0825544731** any time if you have questions about the research or if you are injured as a result of the research.

You may contact the Secretariat of the Health Sciences Research Ethics Committee, UFS at telephone number, 051 401 7795, if you have questions about your rights as a research participant.

Your participation in this research is voluntary, and you will not be penalized or lose benefits if you refuse to participate or decide to terminate participation.

If you agree to participate, you will be given a signed copy of this document as well as the participant information sheet, which is a written summary of the research.

The research study, including the above information has been verbally described to me. I understand what my involvement in the study means and I voluntarily agree to participate.

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Witness  
*(Where applicable)*

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Interpreter  
*(Where applicable)*

\_\_\_\_\_  
Date

# **ADDENDUM I**

DRAFT FRAMEWORKS

PHASE 3

## 5.. Influential factors

### Barriers

- Negative perceptions about social media
- Unreliable mobile phones and networks e.g. electricity
- Limited internet access
- Limited human interaction with mHealth
- High cost → data & phone calls
- Limited skills to operate mobile technology and functions
- Frequent change of caregivers' phone numbers
- Phone sharing among families
- Limited language skills
- Poor knowledge re mHealth services
- Receive non-tailored messages
- Distrust of technology by some caregivers
- Unable to appraise quality of information
- Challenges inherent to SMS/MMS/IVR accessibility and usability
- Rapid rate of technology development
- Policy constraints
- Complex information via IVR - more difficult to listen than read
- Limited message length (160 characters) per SMS
- Concern that mHealth will replace healthcare services
- Telephone "coaching" not always possible in large group settings
- Need skilled workforce to support, maintain and sustain mHealth services.

### Support:

- mHealth technology is flexible, convenient, inexpensive, available and effective
- mHealth technology can be tailored to individual preferences
- mHealth communication less judgemental, pressured, lectured, shamed or frightened to caregivers
- mHealth communication occur in private and comfort of own homes ↓ stigma
- mHealth able to "save and store" information to be retrieved later
- Saves time → both individual (travel) and HCP (pre-record/written messages)
- Improves communication between all support structures
- Needs a very basic, low-cost phones for SMS
- High penetration of mobile phones in Africa
- Involves all policy and community stakeholders
- Variety of mobile phone functions available e.g. SMS, MMS (video & audio), phone calls
- Assist with staff shortages - minimal human resource input needed
- Scalability to deliver information simultaneously to large number of people in hard to reach areas in caregivers own language
- Provides interaction and connection through two-way communication
- Mobile technology: becomes cheaper every year
- mHealth is an enabler of change in the health care sector
- Voice, video and phone call functioning ideal for illiterate caregivers
- Message frequency: improve relationship between recipient and sender.

## 6. Evidence-based

- SMS
- MMS
- Call services

## 1. Assumptions

- mHealth will support rural caregivers
- Involvement of DoH is essential to mHealth initiatives

## 2. Problem

Rural caregivers of adolescents with MH issues do not have adequate support.

## 3. Community needs

- Psychosocial & emotional needs of caregivers
- Caregivers' need information, training and education when caring for the adolescent with MH issues
- Caregivers need clarification on caregiving roles and responsibilities
- Need for coping strategies: control, self-efficacy, problem solving, stress management skills
- Caregivers feel isolated and experience stigmatization in the community
- Caregivers needs assistance with family relationships
- Caregivers need guidance regarding concerns about adolescent's future

## 4. Desired results

- Create structural support: network of people to support caregivers (HCP, co-carers, church and school)
- Implement culturally acceptable initiatives to support caregivers
- Improve caregivers' access to information, advice and training
- Recognise caregiver role and responsibilities
- Offer caregivers concrete strategies to manage daily life and coping skills
- Influence and increase caregivers beliefs, attitude, knowledge, self-efficacy positively towards adolescent with MH issues
- Improve caregivers ability to recognise MH issues among adolescents
- Promote help-seeking behaviour among caregivers
- Mobilize caregivers as change agents and advocates for MH
- Facilitate health dialogue opportunities resonating with caregivers
- Improve caregivers' decision-making and management skills re adolescent care
- Increase caregivers' awareness about available mHealth and MH services
- Acknowledge caregiver well-being
- Align mHealth communication for caregivers of adolescents with national strategies and systems
- Access to quality mental healthcare

## Influential factors 5

### Barriers

- Negative perceptions about social media
- Unreliable mobile phones and networks e.g. electricity
- Limited internet access
- Limited human interaction with mHealth
- High cost → data & phone calls
- Limited skills to operate mobile technology and functions
- Frequent change of caregivers' phone numbers
- Phone sharing among families
- Limited language skills
- Poor knowledge re mHealth services
- Receive non-tailored messages
- Distrust of technology by some caregivers
- Unable to appraise quality of information
- Challenges inherent to SMS/MMS/IVR accessibility and usability
- Rapid rate of technology development
- Policy constraints
- Complex information via IVR - more difficult to listen than read
- Limited message length (160 characters) per SMS
- Concern that mHealth will replace healthcare services
- Telephone "coaching" not always possible in large group settings
- Need skilled workforce to support, maintain and sustain mHealth services

### Support

- mHealth technology is flexible, convenient, inexpensive, available and effective
- mHealth technology can be tailored to individual preferences
- mHealth communication less judgemental, pressured, lectured, shamed or frightened to caregivers
- mHealth communication occur in private and comfort of own homes, stigma
- mHealth able to "save and store" information to be retrieved later
- Saves time → both individual (travel) and HCP (pre-record/written messages)
- Improves communication between all support structures
- Needs a very basic, low-cost phones for SMS
- High penetration of mobile phones in Africa
- Involves all policy and community stakeholders
- Variety of mobile phone functions available e.g. SMS, MMS (video & audio), phone calls
- Assist with staff shortages - minimal human resource input needed
- Scalability to deliver information simultaneously to large number of people in hard to reach areas in caregivers own language
- Provides interaction and connection through two-way communication
- Mobile technology: becomes cheaper every year
- mHealth is an enabler of change in the health care sector
- Voice, video and phone call functioning ideal for illiterate caregivers
- Message frequency: improve relationship between recipient and sender.

## Evidence-based 6

- SMS
- MMS
- Call services
- **Mobile applications**

## Assumptions 1

- mHealth will support rural caregivers
- Involvement of DoH is essential to mHealth initiatives

## Problem 2

Rural caregivers of adolescents with MH issues do not have adequate support.

## Community needs 3

- Psychosocial & emotional needs of caregivers
  - **Caregivers need continuous information, training and education when caring for the adolescent with MH issues**
- Caregivers need clarification on caregiving roles and responsibilities
  - **Need for coping strategies: control, self-efficacy, problem solving, stress management skills and self-knowledge/ awareness**
- Caregivers feel isolated and experience stigmatization in the community
- Caregivers needs assistance with family relationships
- Caregivers need guidance regarding concerns about adolescent's future

## Desired results 4

- Create structural support: network of people to support caregivers (HCP, co-carers, church and school)
- Implement culturally acceptable initiatives to support caregivers
- Improve caregivers' access to information, advice and training
- Recognise caregiver role and responsibilities
- Offer caregivers concrete strategies to manage daily life and coping skills
- Influence and increase caregivers' beliefs, attitude, knowledge, self-efficacy positively towards adolescent with MH issues
- Improve caregivers ability to recognise MH issues among adolescents
- Promote help-seeking behaviour among caregivers
- Mobilize caregivers as change agents and advocates for MH
- Facilitate health dialogue opportunities resonating with caregivers
- Improve caregivers' decision-making and management skills re adolescent care
- Increase caregivers' awareness about available mHealth and MH services
- Acknowledge caregiver well-being
- Align mHealth communication for caregivers of adolescents with national strategies and systems
- Access to quality mental healthcare
  - **Establish mentor- and peer support programs among caregivers**
  - **Re-emphasize primary mental healthcare services.**
  - **Integrate mHealth with current mental health services/system.**
  - **Establish access to Wi-Fi.**
  - **Build on and link to existing mHealth projects (e.g. MomConnect)**

# **ADDENDUM J**

FINAL FRAMEWORK

PHASE 3

## Influential factors ⑤

### Barriers

- Negative perceptions about social media
- Unreliable mobile phones and networks e.g. electricity
- Limited internet access
- Limited human interaction with mHealth
- High cost → data & phone calls
- Limited skills to operate mobile technology and functions
- Frequent change of caregivers' phone numbers
- Phone sharing among families
- Limited language skills
- Poor knowledge re mHealth services
- Receive non-tailored messages
- Distrust of technology by some caregivers
- Unable to appraise quality of information
- Challenges inherent to SMS/MMS/IVR accessibility and usability
- Rapid rate of technology development
- Policy constraints
- Complex information via IVR - more difficult to listen than read
- Limited message length (160 characters) per SMS
- Concern that mHealth will replace healthcare services
- Telephone "coaching" not always possible in large group settings
- Need skilled workforce to support, maintain and sustain mHealth services

### Support

- mHealth technology is flexible, convenient, inexpensive, available and effective
- mHealth technology can be tailored to individual preferences
- mHealth communication less judgemental, pressured, lectured, shamed or frightened to caregivers
- mHealth communication occur in private and comfort of own homes ↓ stigma
- mHealth able to "save and store" information to be retrieved later
- Saves time → both individual (travel) and HCP (pre-record/written messages)
- Improves communication between all support structures
- Needs a very basic, low-cost phones for SMS
- High penetration of mobile phones in Africa
- Involves all policy and community stakeholders
- Variety of mobile phone functions available e.g. SMS, MMS (video & audio), phone calls
- Assist with staff shortages - minimal human resource input needed
- Scalability to deliver information simultaneously to large number of people in hard to reach areas in caregivers own language
- Provides interaction and connection through two-way communication
- Mobile technology: becomes cheaper every year
- mHealth is an enabler of change in the health care sector
- Voice, video and phone call functioning ideal for illiterate caregivers
- Message frequency: improve relationship between recipient and sender.

## Evidence-based ⑥

- SMS
- MMS
- Call services
- Mobile applications

## Assumptions ①

- mHealth will support rural caregivers
- Involvement of DoH is essential to mHealth initiatives

## Problem ②

Rural caregivers of adolescents with MH issues do not have adequate support.

## Community needs ③

- Psychosocial & emotional needs of caregivers
  - Caregivers need continuous information, training and education when caring for the adolescent with MH issues
- Caregivers need clarification on caregiving roles and responsibilities
  - Need for coping strategies: control, self-efficacy, problem solving, stress management skills and self-knowledge/ awareness
- Caregivers feel isolated and experience stigmatization in the community
- Caregivers needs assistance with family relationships
- Caregivers need guidance regarding concerns about adolescent's future

## Desired results ④

- Create structural support: network of people to support caregivers (HCP, co-carers, church and school)
- Implement culturally acceptable initiatives to support caregivers
- Improve caregivers' access to information, advice and training
- Recognise caregiver role and responsibilities
- Offer caregivers concrete strategies to manage daily life and coping skills
- Influence and increase caregivers' beliefs, attitude, knowledge, self-efficacy positively towards adolescent with MH issues
- Improve caregivers ability to recognise MH issues among adolescents
- Promote help-seeking behaviour among caregivers
- Mobilize caregivers as change agents and advocates for MH
- Facilitate health dialogue opportunities resonating with caregivers
- Improve caregivers' decision-making and management skills re adolescent care
- Increase caregivers' awareness about available mHealth and MH services
- Acknowledge caregiver well-being
- Align mHealth communication for caregivers of adolescents with national strategies and systems
- Access to quality mental healthcare
  - Establish mentor- and peer support programs among caregivers
  - Re-emphasize primary mental healthcare services.
  - Integrate mHealth with current mental health services/system.
  - Establish access to Wi-Fi.
  - Build on and link to existing mHealth projects (e.g. MomConnect)