Impact of Availability and Quality of Psychosocial Services on Treatment Adherence amongst Adolescents Living with Cancer in Low-and Middle-Income Countries: A scoping Review

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STUDENT DECLARATION

I, Innocensia Kambewe (student number: 1505689) am a post graduate student registered for the Master of Public Health, at Wits School of Public Health. I declare that this research project on the Impact of Availability and Quality of psychosocial services on treatment adherence amongst adolescents living with cancer in Low to Middle Income countries is my own original work. I am submitting this research report to the School of Public Health at the University of the Witwatersrand, Johannesburg, for the Degree of Public Health in Social Behavior Change Communication. Any work by other authors quoted or used in this report has been cited appropriately. This research report has not been submitted for assessment at this or any other institution.

Signature:

Innocensia Kambewe Date:11 December 2024

Dedication

To the adolescents in LMICs going through cancer without proper psychological and social services to make treatment easier and less taxing, may this be a foundation for more research that pushes forward effective policies and services that aid in increasing adherence to treatment.

To my mother, whose relentless support paved the way through the completion of this journey, my sister Irene, whose pursuit in the academics has always been a great inspiration and to my sister Ingrid who has always been the light that empowered me towards my goal despite the ups and downs.

Abstract

Introduction: A cancer diagnosis during adolescence can have a significant impact on the psychosocial well-being of adolescents and their caregivers. Psychosocial well-being is a state of emotional, mental and social environment that influences the functionality of individuals. Adolescents are influenced by their social environment; this can affect their physical wellbeing especially when going through cancer treatment. In 2017, globally over 11.5 million disability-adjusted life years (DALYs) were recorded for cancer frombirth to 19-year-olds, this proportion was mostly concentrated in Africa, Central and South America and in Asia. The burden of cancer among adolescents in Low- and Middle-Income Countries (LMICs) is a weight that conveys the inequity in the distribution and control of cancer care resources worldwide. The study aimed to describe the psychosocial services that are available for adolescents living with cancer and the relationship between the availability and quality of psychosocial services on treatment adherence among adolescents in LMICs.

Methodology: A scoping review following the PRISMA reporting guidelines was used to investigate the extent, variety, and characteristics of literature on adolescent psychosocial services that contribute to cancer treatment adherence. Data was collected from online databases including Cochrane, Embase, PubMed/MedLine, and Science Direct, websites, and through citation scanning. Data was then charted in a Data Extraction form and was analyzed to acquire results.

Results: Six articles that demonstrated the impact that availability and quality of psychosocial services had on treatment adherence among adolescents going through oncology treatment were included in this scoping review. Psychological, educational and community services were identified as psychosocial services that impact cancer treatment adherence among adolescents in LMICs.

Conclusion: Our review found that available and high-quality psychosocial services among adolescents with cancer increases treatment adherence in LMICs may be lacking. More research needs to be done on the quality of psychosocial services and their impact on cancer treatment adherence in developing countries.

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Tables and Figures

List of abbreviations

LMICs	Low- and Middle-Income Countries
HICs	High Income Countries
AYAs	Adolescents and Young Adults
DALYs	Disability Adjusted Life Years
CBT	Cognitive Behavioral Therapy
PMT	Protection Motivation Theory
CCPs	Childhood cancer patients
HCPs	Health care professionals
TREAT	Time Responsive Electronic Abandonment Tracking System
CHOC	Childhood Cancer Foundation South Africa
CANSA	The Cancer Association of South Africa
ZACCAF	Zambian Childhood Cancer Foundation
CMJAH	Charlotte Maxeke Johannesburg Academic Hospital
RCTs	Randomized Control Trials
PICO	Populations, Interventions, Comparisons and Outcomes

Chapter 1 Introduction

1.1 Background

A cancer diagnosis during adolescence can have a significant impact on the psychosocial well-being of adolescents and their caregivers. Cancer in adolescents can be caused by exposure to ultraviolet lights from the sun, prior chemotherapy treatments, a human immunodeficiency virus (HIV) infection, some lifestyle choices like using tanning beds or smoking (these are attributed to older young adults) and many more (1). In 2017, globally over 11.5 million disability-adjusted life years (DALYs) were recorded for cancer from birthto 19-year-olds, this proportion was mostly concentrated in Africa, Central and South America and in Asia (2).

The number of new cancer cases across all age groups globally is estimated to increase to 22.2 million by 2030 (3). Moreover, Africa's cancer incidence rates arepredicted to increase by 70% between 2012 and 2030 with more than 80% of child oncology patients living in Low-Middle-Income-Countries (LMICs) (2) (3). To top this off, childhood cancers were recorded as the sixth leading cause of the global cancer burden (2). Globally, childhood cancer DALYs were reported to be at 82.2% (2). The five-year overall survival rates in LMICs ranges from 5 to 60% LMICs having only 5% of global cancercare resources at their disposal will actively affect the cancer care system hence putting a strain on health care workers in turn affecting the care they provide (2) (4).

In 2019, global cancer incidence among 15- to 39-year-olds was 1.19 million with 396 000 cancer deaths (5). Cancer incidence rates increased in 2022 to 1.3 million cases while deaths decreased to 377 621 deaths among AYAs. Females were affected by cancer more than males with respective incidences of females 52.9 per 100 000 and males 28.3 per 100 000. In 2024, 14 910 children and adolescents aged zero to 19 years old will be diagnosed with cancer in 2024 and 1 590 will die of cancer (5).

In 2012, 65% of cancer deaths occurred in Low-Middle- Income countries (LMICs) and was projected to rise to 75% as of 2023 (6). For adolescents aged 15 to 19 years old the most common cancers range from cancer ofthe testes, ovaries and thyroid which contribute to the second highest DALY recordedglobally by 19.5% (2). Moreover, more than 80% of all children and adolescent oncology patients go into full remission in High-

Income Countries (HICs) unlike in LMICs where only 30% are able to go into remission (7). The burden of cancer amongadolescents in LMICs is a weight that conveys the inequity in the distribution and control of cancer care resources worldwide (8). Additionally, the lack of accurate cancer rate surveillance for adolescents in LMICs is among the main contributors to the rise in adolescent cancer mortality rates (7). Without proper surveillance, there willbe no proper way to ensure resource planning and health policy prioritization is done at its best (2). This inadequacy in resources is a consistent barrier to cancer treatment and a cause for a multitude of psychosocial service inadequacies in LMICs (9). Making it a much more complicated battle than just taking care of an adolescent's health andensuring remission.

1.1.1. Adolescents with cancer

Adolescence is a pivotal period for growth and development, according to WHO this period starts from 10 to 19 years old (10). Findings show that adolescents go through rapid cognitive and emotional growth during this time (11). The period of adolescence pushes for academic accomplishments, immediate social interactions and the need for personal development which puts adolescents at a disadvantage (12). This is because adolescents are mostly focused on their present experiences making the consequences of cancer feel more acute, affecting their mental health through depression, anxiety, and many others (12). Depressive symptoms, poor self-concept, a lack of motivation, egocentrism and a lack of awareness when it comes to their own cancer treatment plan are among few of the unique challenges that adolescents with cancer experience when living in LMICs (13). Additionally, a lack of cancer knowledgeand access to cancer treatment has repeatedly resulted in barriers to patient'spsychological and cognitive functioning which inherently affects the patient's adherence to treatment (13). Treatment adherence is directly linked to survival, qualityof life and overall treatment outcomes and with proper adherence strategies adolescent can maximize the efficacy of treatment while avoiding drug resistance, in turn improving their chances of survival and treatment outcomes (14-15).

1.1.2. Psychosocial services to improve adolescent treatment outcomes

Psychosocial health is essential for adolescents going through cancer treatment. Despite the confusion on the definition of psychosocial health, it has been commonly described as a multidisciplinary construct that encompasses the mental, emotional, and social health of an individual. The East African Community defines psychosocial

well-being as the development of cognitive, emotional, and spiritual strengths in individuals and communities. That leads to positive relationships between people and within communities (16). This is why incorporating psychosocial services for oncology adolescent patients is important because these factors contribute to their treatment adherence. Factors like proper mental health, a community, emotional stability, or a positive social environment can improve treatment outcomes for this population (17).

Evidence shows the positive impact psychosocial services can have for adolescents with cancer. Adolescents going through oncology treatment need psychosocial services to ensure they do not lose themselves in their treatment protocolbut thrive in tandem with it. This population experiences cancer very differently from children and adults and this is due to the developmental phase adolescents go throughduring this period (18). With adverse psychosocial and emotional outcomes, psychosocial interventions were found to have a positive effect and increase in treatment adherence among adolescents (19). This is why psychosocial services should be addressed because they provide adolescents with cancer the tools to sustainably overcome the effects of cancer treatment (12). As shown in a randomized control trial on children (mean age 13.2 years) with cancer, weekly physical exercising and psychosocial training in the form of psycho-education and cognitive behavioral therapies (CBT) directly improved treatment adherence (20). A systematic review alsolooking into the effectiveness of psychosocial interventions on cancer patients under 18 years found positive psychological outcomes through the introduction of joint CBT, physical exercise therapy, family therapy, therapeutic music videos, self-coping strategies and joint family therapy, suggesting its probable effect on improved cancer treatment adherence within this population (21).

Health care in LMICs needs to integrate psychosocial services into adolescent oncology treatment plans to tackle the very distinctive challenges adolescents face during this time. Research suggests the need for psychosocial service provision to adolescent patients and their families as it positively affects the transition into the treatment period for both parties (16). A study looking into psychosocial assessment as a standard of childhood cancer care found that the implementation of consistent psychosocial assessments will aid in early detection of ailments that may psychologically, physically, socially and or financially affect the treatment regime over time (16). Thus, the implementation of these services may have a positive effect on cancer treatment adherence within this population because adherence is an indicator

for treatment success (22). Psychosocial services are of high significance in increasing the rates of adolescent cancer treatment adherence in LMICs as evidently proven in adolescent cancer treatment among developed countries (23).

1.1.3. Treatment adherence among adolescents with cancer in LMICs

The long duration for most child or adolescent oncology treatment protocols have been linked to low rates of treatment adherence (24). As the duration for these treatments take longer than a year, coupled with the complexity of said treatments contribute to non-adherence resulting into poor treatment outcomes (24). This is because long term cancer treatment protocols can be a cause for inconsistent medication use, not adhering to clinic appointments for chemotherapy sessions or consistent check-ups and failure to participate in self-care behaviors (24). Additionally, in adolescents and young adults (AYAs), there is more resistance to adherence specific to oral chemotherapy, with 60% of AYAs failing to adhere to the recommendations made by their medical teams (22). Furthermore, non-adherence to treatment may result in decreased survival of pediatric cancer patients while increasing the risk of relapse (25). To top this off, the transition from childhood to adolescence also highly affects non-adherence rates as it brings about changes and an increase in responsibility to manage their own medications. Due to the rapid switch in medication administration systems and adolescent having to navigate new schedules while still needing independence, this causes inconsistencies in medication administration hence bringing about non-adherence to cancer treatment regimens (26). With this change, research has shown that adherence decreases as rapidly as 6% daily medication intake to as much as 40% among adolescents (27).

In a study done in Egypt, 64% of children or adolescents had to be admitted for their 3rd chemotherapy session, due to lack of adherence of treatment in their first two sessions. Of the 64%, 68% were recorded to not have adhered to their treatment and or at home treatment recommendations (28). A study done in India indicated that

cancer treatment abandonment rate of pediatric acute Myeloid Leukemia in India ranges from 19% to 50% among the sick children or adolescents (29). These alarming rates of cancer treatment non-adherence among adolescents in LMICs underscore the need for targeted services and programs together with psychosocial support systems that can address cancer treatment non-adherence among adolescents in LMICs.

1.2. Problem statement

While cancer in adolescents is rare in terms of burden of disease it poses challenges for families and for health care systems in LMICs (15). Standard cancer treatments are available in LMICs however for them to be successful adherence is essential. In LMICs, there is limited availability of resources, infrastructural, and financial constraints faced by both families and the country as a whole which contributes to non-adherence (30). Emphasizing the need for research on adolescent cancers. Through synthesis of literature in this field, the findings will aid in identifying factors that cause cancer treatment non-adherence hence assisting in creating programs and policies to facilitate successful adherence (30).

There are many psychosocial challenges for adolescents undergoing cancer treatment (16). Understanding how these challenges affect adherence to cancer treatment is essential. The findings of this research can be integrated into adolescent cancer care systems in LMICs and aid in implementing and developing psychosocial services, interventions or programs that will increase cancer treatment adherence among adolescents in LMICs. Through this research we aim to bring forth any key areas where improvements are needed to better cater to the unique needs of our population group. Hence impacting the way adolescents with cancer in LMICs are treated.

1.3. Justification for Study

In light of the presented challenges, research on the availability and quality of psychosocial services for adolescents with cancer needs to be made a priority to ensure interventions, programs, and hospital or health government policies are well informed. Research shows that understanding the specific gap in psychosocial literature can actively aid in improving advocacy efforts and overall access to psychosocial services

in LMICs (31). The need for high quality and accessible psychosocial services is often overlooked, especially among adolescents in LMICs. Another gap is the role of psychosocial services in treatment adherence, the findings of this study will aid in providing evidence that can be used to advocate for improved standards of care Not taking the time to understand this gap in psychosocial literature can be a cause for delay in curating a standard of care that best fits adolescent oncology patients in LMICs.

This study investigated the gaps in literature on the availability of psychosocial service support systems and identified where there is a need for more to be done to ensure adolescents going through oncology treatment in LMICs get the support they need to maintain treatment adherence.

1.4. Research Question

What is the impact of availability and quality of psychosocial services on treatment adherence in adolescents aged 10 to 19 years old living with cancer in LMICs?

1.5. Research Aim

The study aimed to describe the psychosocial services that are available for adolescents living with cancer and the relationship between the availability and quality of psychosocial services on treatment adherence among adolescents in LMICs.

1.6. Objectives:

1. To describe the characteristics of psychosocial services provided for adolescents living with cancer in LMICs, including the types of services, and the delivery modes.
2. To investigate the relationship between availability and quality of psychosocial services on cancer treatment adherence for adolescents aged 10 to 19 years in LMICs.
3. To identify gaps in existing literature and areas for further research on psychosocial services on cancer treatment adherence for adolescents aged 10 to 19 years in LMICs.

1.7. Literature Review

Globally, cancer incidence rates will keep rising and the effect will mostly fall within LMICs. Despite the incidence and prevalence rates of cancer in LMICs being two thirds of theglobal population, the allocated cancer global budget this region uses is only 6.2% (8).Given these disparities, it is urgent that unequal resource distribution is addressed, and strategies are put in place to improve cancer care in LMICs.

Research shows a shortage in cancer treatment in LMICs; these shortages were observed in chemotherapy drugs, antimicrobials and supportive care drugs (such as pain medication) (32). This study went on to analyze the availability of childhood cancer treatments and found among 10 LMICs, only three (Egypt, Ukraine and Venezuela) provided access to radiotherapy, chemotherapy, blood products, and antimicrobials (32). Additionally, low levels of education, a lack of health-related knowledge and delaying to seek medical attention are common factors among parents of children with cancer symptoms (33). This prompts high rates of cancer treatment abandonment, ranging from 25% to 50% in LMICs (8,34).

1.8. Psychosocial services for adolescents with cancer in LMICs

1.8.1. Types of psychosocial services in LMICs

More research is needed on the psychosocial services provided for adolescents with cancer in LMICs. Providing psychosocial services to adolescents during their cancer treatment is essential to ensure that this period of their lives is not as difficult as it normally is. Research found that addressing the needs of adolescents during oncology treatment is essential in the delivery of quality cancer care (35). The needs identified

include psychological comorbidities like depression, anxiety, low self-esteem, low self-efficacy and a poor sense of self are cultivated by the side effects of not only the diagnosis but the cancer treatment as well (36). For adolescents to adhere to treatment, the emotional, social and developmental impacts of a cancer diagnosis need to be managed in tandem with their treatment (37). These needs will keep affecting the adolescent during their cancer treatment regime which is why integrating consistent psychosocial services is crucial for their well-being.

1.8.2. Psychosocial service delivery

The delivery of psychosocial services to adolescents with cancer needs to be analyzed to ensure they are getting the right treatment support for their particular challenges. Technology based interventions can be a great way to interact with peers without the need for movement, hence increasing the accessibility of peer support systems for adolescents going through cancer. A good example of these are interactive websites and or video as well as online games (38). Research reports that through education on average these sets of activities increase self-efficacy and knowledge of disease among adolescents. When adolescents have a better understanding of their cancer and their treatment plan by understanding what the cancer is, why they are going through treatment, the side effects of said treatment and the significance of adhering to treatment it is easier for them to adhere to treatment (39). This shows the significance of integrating psychosocial interventions or services into adolescent cancer treatment regimes.

About 50% of adolescents going through cancer want to meet peers who are affected by cancer as well, but these needs are not being readily met (40). Having space and time to interact with their peers provides adolescents with the opportunity to speak openly about their fears, their pain and everything they are forced to deal with that accompanies a cancer diagnosis (41). Despite this observation, studies have found low levels of social support, low levels of cancer literacy and an avoidant coping system are characteristics of adolescents who are not interested in psychosocial care while they are the ones that need psychosocial services the most (42). This gap between desire to have these services and the provision of said services underscores a gap in research that presents an area for improvement of psychosocial service

provision. Introducing more accessible services or ways to interact with their peers could be a great way to bridge this gap.

1.9. Relationship between psychosocial services and treatment adherence in adolescents

1.9.1. Cancer treatment adherence in adolescents

As outlined through studies, the factors that affect adherence among adolescents range from individual to economic and may extend to geographic factors (43). Research further identified inadequate support systems and lack of understanding of the need for medication as factors that affect adherence (18). Furthermore, poor communication between the adolescent patient and health care workers increases non-adherence especially if the health care worker was not able to communicate the significance of adherence to the adolescent (18). Non-adherence is economically driven in LMICs; as seen in a study on Zimbabwean women aged 12 and above who were financially capable, were able to access cervical cancer services in comparison to ones who did not have the financial capabilities (44). Geographical location is to be considered as seen in the same study young women who lived in mining villages were more likely to have access to these services in comparison to those living in traditional rural reserve villages (44). Additionally, the women who reside in resettlement villages or towns were about 20% more likely to not have access to any cervical cancer screening services that those in traditional rural reserve villages (44). Among these women aged 12 and above, which included adolescents and young adults, individual factors such as forgetting to take medication and having lifestyle distractions were clearly noted to affect adherence to treatment (44). Another study pointed out a lack in physical and social support for medication taking was as a definite factor for non-adherence among young adults (45).

Adolescents going through oncology treatments are prone to experiencing non-adherence to treatment in LMICs. This can be seen in Kenya where 222 children were newly diagnosed with a malignancy and among 180 patients included into the study, 72% of them abandoned treatment after the first three months of chemotherapy. Of the percentage that abandoned treatment nine were still alive (six looking healthy while three looked very ill) and 37 of these children had passed away (15). Non-adherence can also be seen in Northern Vietnam, where within the study population (677

children), 45.5% of their parents denied any curative care for their children before and during treatment (35). This shows how prominent adherence issues are within adolescents in LMICs, stressing the significance of ensuring regularity and consistency in taking medication and performing tasks advised to ensure adherence. These instances of non-adherence in LMICs highlight the necessity for implementing targeted psychosocial services that cater not only to the adolescents themselves but to their families as well.

1.9.2. Significance of Treatment adherence for Adolescents with cancer

Cancers like leukemias, sarcomas and lymphomas where a long-term treatment plan is needed, puts adolescents and young adults at a higher risk of non-adherence due to the nature of the treatment protocol (46). Research shows that with proper adherence strategies AYAs can maximize the efficacy of treatment while avoiding drug resistance, in turn improving their chances of survival and treatment outcomes (14). Similar work was done, and findings showed during adolescence, adhering to cancer treatment highly impacts the psychosocial components of an adolescent's life (47). It limits an adolescent's social interactions, ability to learn and independence, it also changes the way adolescents look at their bodies hence causing issues with low self-esteem (47). This is why adhering to treatment as an adolescent may not be as appealing as it should be despite the significance it has to positive and long-term health outcomes. Research that focuses on treatment adherence for this population is crucial in understanding how difficult it is for adolescents and young adults to adhere to cancer treatment. Especially because findings show that adhering to cancer treatment for adolescent cancer survivors' aids in long lasting effects on their health outcomes and possibility of recurrence (48).

1.9.3. Psychological and social factors influencing Treatment Adherence in Adolescents with cancer

To have the best grasp on adolescent cancer treatment adherence, it is crucial to understand the psychological and social aspects that contribute to poor adherence within this population group. Social factors such as denial of illness, conflict within family, loss of control, changes in routine, loss of self-esteem and body image issues can greatly affect how adolescents interact with their cancer treatment protocol (12). Adolescent dependency on parents and parents' refusal to encourage independence

in their children is a psychological factor that affects treatment adherence in adolescents. This inadvertently affects treatment adherence as it delays the adolescent's ability to take responsibility for their treatment (18). This is mostly due to the consequences of treatment that the parent tends to witness. Going through cancer treatment with a child puts parents and caregivers at the forefront of their children's pain, prompting a need to protect them which may sometimes lead to overprotection (18).

While going through a developmental stage that alters their whole perception of self and how they interact with others, adolescents diagnosed with cancer also must go through their cancer treatment regimen (49). Findings show that with this life-threatening diagnosis also comes invasive treatments with side effects like hair loss, vomiting, diarrhea, changes in their skin, pain and insomnia. Thus, significantly impacting the quality of life among adolescents leading to psychological strains and burdens (49). These strains and burdens need to be directly addressed as they will add to the challenge of transitioning from childhood to adulthood, another psychosocial factor that contributes to poor adherence among this population (49). Research emphasizes the significance of the lack of independence that accompanies a cancer diagnosis among adolescents (50). During this time, independence is somewhat of a currency among adolescents as it provides them with the freedom to grow as they please (50). With a cancer diagnosis comes dependency and findings suggest that this increased dependency on parents creates a barrier between them and their peers inciting feelings of loneliness because at this age peer acceptance is crucial to this population (50,32).

1.9.4. Psychosocial services availability and quality

Sustainable change will be hard to achieve with inconsistencies in the systems placed to ensure cancer regimes and treatment protocols are handled correctly for adolescents. Several studies have explored the effects of poor health systems for adolescent cancer patients, and how these system barriers are affecting access to psychosocial care for adolescents. A study found that psychosocial services were not being offered to adolescents with cancer and if they were, they were inconsistent with the offerings (51). The inconsistencies reflect their inability to fully integrate psychosocial services into the community as they should, hence portraying inequities and barriers to receiving appropriate psychosocial support during treatment (51).

Conceptually similar work has been carried out and results suggest that service related and systemic barriers are factors affecting psychosocial service provision to adolescents with cancer (52). The multifactorial nature of these barriers, and how they are dependent on a vast number of factors like environment or financial factors is a gap that needs to be addressed to ensure the availability of quality psychosocial services in LMICs (52).

1.10. Gaps in research on Psychosocial services and cancer treatment adherence

1.10.1. Gaps in Research

There is limited research on psychological and social factors that contribute to cancer treatment adherence within the adolescent population. This is a setback as the majority of research focuses on chemotherapy medication and attending chemotherapy sessions, keeping in mind that adherence is largely and mostly affected by behaviors and the environment a patient is in (53). More in-depth research on the psychosocial factors that affect treatment adherence among adolescents and young adults to create sustainable change within this population.

Chapter 2: Methodology

A scoping review following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) reporting guidelines was used to investigate the extent, variety, and characteristics of literature on adolescent psychosocial services that contribute to cancer treatment adherence. This scoping review also aimed to outline evidence on the area of interest and potential gaps for further research. We employed a five-step framework for conducting scoping reviews as outlined by Arksey and O'Malley in their paper, namely: 1) identifying the research question, 2) identifying relevant studies, 3) study selection, 4) charting the data, 5) collating, summarizing, and reporting results (54).

2.1. Identifying the research questions

Insights from the Cancer Association of South Africa (CANSA) highlighted a significant gap in the addressing of cancer services for adolescents which in turn revealed the large gap in access to cancer care and support. This prompted us to look further into the literature and review the landscape of health issues affecting adolescents in LMICs, including issues such as HIV. In spite of the higher mortality rate in HIV adolescents with every one in three new HIV infections in South Africa occurring among 15 to 24 year olds, there has been a constant decrease in HIV incidence rates due to the focus placed on access to antiretrovirals, knowledge and awareness of this disease among the adolescent population (2,6). Comparative to cancer among adolescents in a LMIC, where in 2019 only 506 cases were recorded among 10 to 19 year olds (54). Despite the lower incidence rates in LMICs, cancer still poses more of a threat to the population due to its unique challenges. Issues such as lack of affordable care, poor support and surveillance systems, little to no psychosocial support, and lack of early diagnosis; all that contribute to poor cancer treatment adherence outcomes (35). A study of 684 adolescents (10 to 19 years old) with HIV focused on improving adherence reported adolescents sticking to their drug regime after being provided with the knowledge of their HIV status and knowledge on the diseases itself (55). Another study evaluated the VUKA family program that provided psychosocial interventions to adolescents with HIV and found improvement in all sectors, mental health, disease knowledge, stigma, communication and most importantly adherence to medication. This comparison illuminates the significance of

improving cancer research on cancer care through drawing lessons from these successful HIV studies.

Moreover, this cursory review of the literature indicated a lack of evidence on psychosocial service interventions supporting treatment adherence in adolescents with cancer, especially in LMICs. It also indicated the possibility and success of psychosocial interventions and studies that focus on chronic disease treatment adherence for adolescents, pushing forward the need to conduct this study.

This scoping review aims to describe the psychosocial services that are available for adolescents living with cancer and the relationship between the availability and quality of psychosocial services on treatment adherence among adolescents in LMICs.

2.1.1. PCC framework

To clearly formulate our research question, we employed the Population, Concept, and Context (PCC) framework to identify specifically what our research question needs, to capture the best results. Employing this framework aided in developing our search strategy through incorporating the defined PCCelements into our search terms and strategies (56). The PCC framework is well suited for this scoping review due to its exploratory nature without a need to focus on interventions only.

Equally important is the documentation of the research process, using the PCC framework made it easy to record any changes to the definitions of the components which in turn increases transparency, validity, and reproducibility when reporting. The PCC framework also aided in defining our inclusion and exclusion criteria when screening for literature that can be found in Appendix 2 of our research report.

This is how we defined our Population, Concept, and Context (PCC);

2.1.1.1. Population

We focused on adolescents aged 10 to 19 years old as defined by the WHO. Through research we came to the realization that people aged 10 to 19 years old can be referred to as adolescents, teenagers, children, young adults, and youth. This informed the creation of our search strings and aided in theexpansion of our search strategy.

LMICs was also a point of focus in the population group, in this review we incorporated synonyms and words that relate to LMICs such as developing countries, and the LMICs

term was broken down into low-income countries and middle-income countries. In addition to this, we incorporated all LMICs according to the World Bank (60). This bettered our findings, adding on studiesthat were not indicated to be LMICs in the title or abstracts but were still conducted in LMICs.

2.1.1.2. Concept

The varying levels of availability and quality of psychosocial services foradolescents in LMICs and its effect on treatment adherence was our concept group. We initially found that the available literature mostly spoke on our population group receiving standard care for cancer without the added psychosocial services. Likewise, studies were mostly focused on identifying psychosocial services being used without evaluating them on the effects they had on treatment adherence. It was a brief description that did not provide a deeper understanding of the effects of psychosocial support to draw significant conclusions. This prompted a more critical view and refinement of the structure of our search strings and search strategy.

To refine our search strings, we broke down the key concepts of our research question, starting with psychosocial services into psychological and social services. We used synonyms for treatment adherence such as treatmentcompliance and more will be mentioned below. With impact and availability, wedissected it into more specific key concepts; availability of psychosocial services which entail active support and times of service availability. Technological access to services which entails the availability of online, digitalplatforms and mHealth platforms to easily access these services for adolescents. The range of provided services was also added and competencyand perceptions of psychosocial health care providers were also looked at. Communication and language barriers were also addressed together with stigma and peer acceptance. All the mentioned above support or hinder the impact and availability of psychosocial services for adolescents in treatment adherence, thus integrating them into our search aided us in finding more specific studies tailored to our broad topic.

2.1.1.3. Context

LMICs are the specific context for this scoping review. We employed the World Bank LMCIs list to ensure the review has covered the entirety of the needed context. Employing this list made the search contextual, covering more specific countries in the LMIC regions.

We used the names on this list to create our search strings that were use to collect the

data from databases. We did this through attaching eight to 10 countries in each search string we created. Together with the list of countries, synonyms of LMICs were used to expand our search; terms like low-income countries, low-income country, middle income countries, middle income country, developing country, and developing countries were used.

2.2. Identifying relevant studies

A comprehensive search was done in Cochrane, Embase, PubMed/MedLine, and Science Direct. Prior to this, a preliminary search was conducted to identify key concepts and keywords in tandem with our PICO framework. The identified keywords were used to build search strings, Boolean words (AND / OR) were combined with the keywords to create multiple search strings that will aid in performing a comprehensive search of our literature.

The search strings were created by the primary researcher and shared with supervisors to develop and refine them. To perform an exhaustive search, the use of uniform search strings was essential across all databases to ensure a comprehensive retrieval and identification of the most relevant literature. After a quick search using the search strings specifically on PubMed/MedLine and Embase, it was imperative that the search strings were adapted to fit these databases. This is because during the initial search, a significant number of the studies we pulled were predominantly focused on the medical aspects of cancer treatment and adherence rather than psychosocial services and adherence. With this, database specific indexing became a priority to ensure we acquire the best results for our research objectives from each database.

We took some time to understand the indexing systems for both databases; we ensured we were familiar with MeSH term for PubMed/MedLine and Emtree terms for Embase. We went on to map our selected keywords to the closest matching indexed terms in these two databases. A quick example is how “adolescent health services” was changed to “Adolescent health care” according to Emtree terms and to “Adolescent Health Services” according to MeSH terms or “treatment adherence” will change to “Medication Adherence” in MeSH terms and “treatment compliance” for therapies that are not drug related in Emtree terms. After applying these changes to our search strings, the results we acquired from these databases were much more tailored to our research aim but there was still a need to filter and add field tags to

acquire better literature. These field tags were year 2000 to present and English or with English translations.

This was done to minimize selection bias, and work towards a more comprehensive review of the literature available on our study aim.

2.3. Search terms

The study the search terms were created based on the study objectives. The main elements used to create them were: “cancer”, “low and middle countries”, “adolesce*”, “treatment adherence” and “psychosocial intervention”.

Adolescent related search terms were “adolesce*” OR “teen*” OR “youth*” OR “child*” OR “young adult*”.

Cancer related search terms were "Neoplasms" OR “cancer” OR “malignancy”.

Low to middle income country search strings were "Developing Countries" OR “LMICs” OR “low-income countr*” OR “middle-income countr*” OR Afghanistan OR Korea OR "South Sudan" OR "Burkina Faso" OR Liberia OR Sudan OR Burundi OR Madagascar OR "Syrian Arab Republic" OR "Central African Republic" OR Malawi OR Togo OR Chad OR Mali OR Uganda OR "Democratic Republic of Congo" OR Mozambique OR "Republic of Yemen" OR Eritrea OR Niger OR Ethiopia OR Rwanda OR Gambia OR "Sierra Leone" OR "Guinea-Bissau" OR Somalia OR Angola OR Iran OR Jordan OR Algeria OR Samoa OR "Islamic Republic of Iran" OR "São Tomé and Principe" OR Benin OR Senegal OR Bhutan OR Kiribati OR "Solomon Islands" OR Bolivia OR "Kyrgyz Republic" OR "Sri Lanka" OR "Cabo Verde" OR "Lao's People Democratic Republic" OR Tanzania OR Cambodia OR Lebanon OR Tajikistan OR Cameroon OR Lesotho OR Timor-Leste OR Comoros OR Mauritania OR Tunisia OR Micronesia OR "Côte d'Ivoire" OR Mongolia OR Uzbekistan OR Djibouti OR Vanuatu OR "Egypt" OR Myanmar OR Eswatini OR Nepal OR Zambia OR Nicaragua OR Zimbabwe OR

Guinea OR Haiti OR "Papua New Guinea" OR Albania OR Fiji OR "North Macedonia" OR Argentina OR Gabon OR Palau OR Armenia OR Georgia OR Paraguay OR Azerbaijan OR Grenada OR Peru OR Belarus OR Russian OR Belize OR Serbia OR "Bosnia and Herzegovina" OR Iraq OR Botswana OR Jamaica OR "Saint Lucia" OR Brazil OR Kazakhstan OR "Saint Vincent and the Grenadines" OR Bulgaria OR Kosovo OR Suriname OR Libya OR Thailand OR Colombia OR Malaysia OR Tonga OR "Costa Rica" OR Maldives OR Türkiye OR Cuba OR "Marshall Islands" OR Turkmenistan OR Dominica OR Mauritius OR Tuvalu OR "Dominican Republic" OR Mexico OR "West Bank and Gaza" OR Moldova OR "Equatorial Guinea" OR Montenegro OR Ecuador OR Namibia.

Treatment adherence search terms were "Treatment Adherence" OR "Medication Adherence" OR "Patient Compliance" OR adherence OR compliance OR “treatment compliance”.

Psychosocial services search terms were "Psychosocial Intervention" OR Counsel* OR "Art Therapy" OR "Music Therapy" OR Psycho* OR "Support Groups" OR "Patient Education" OR "psychosocial education" OR “meditation” OR “yoga” OR “guided imagery” OR “breathing exercises” OR “stress reduction”.

The use of asterisks (*) and quotation marks (““) was consistent throughout the databases. In all the databases, asterisks were used as truncation symbols to search for words with a singular root word but multiple endings. Like the use of an asterisks in child* when inserted into the databases, it retrieved literature with child, childhood, and children in either the title abstract and/or keywords presented in the paper.

The use of Quotation marks was consistent throughout the search databases. Quotation marks were placed when looking for exact phrases in literature, phrases like “treatment compliance” or “social support” when placed like this in the search bar they retrieved studies with the exact terms in their titles, abstracts or keywords presented in the paper. Learning and understanding how to rightfully employ the use of asterisks, wildcards and quotation marks helped when it came to efficiently gathering literature needed.

2.4. Study Selection

Prior to the initial title screening, all the literature gathered was imported into Zotero to manage the references, duplicates were then removed using the same reference managing platform. Deduplication was done based on the similarities in the Titles, Author names and DOI's for an efficient screening process and to allow for a succinct presentation of literature gathered as shown in the PRISMA flow diagram. The literature was then uploaded onto Rayyan (a web and mobile app for systematic data reviewing) to begin the title screening (57). Titles were first independently screened by the primary researcher, the articles included were based on the PICO framework and the formulated search strings. Non-conventional literature sources like protocols, dissertations, government reports, websites, and references scanned were included. Articles were also to be included only if they were in English or have an English translation and if they were from year 2000 going forward.

The exclusion criteria comprised of articles not in LMICs according to the World bank list; studies targeting adult cancer patients, non-English papers without translation, and studies not focusing on psychosocial services. Limits were also placed on the study timeline, only literature from 2000 to present. This is because our primary data search showed a lot of adolescent study disparities in parameters between the studies in the early 1900s and early 2000s. Moreover, due to globalization, industrialization, and this new era of technology there would be vast differences in the kinds of psychosocial interventions adolescents will respond to now in comparison to before the 2000s.

After the initial title screening the abstracts were screened by two reviewers (the primary reviewer and a second reviewer) and conflicts were resolved by the supervisors. The inclusion criteria for this step were the population group in the range of 10 to 19 years old, so studies on four- to 15-year-olds would be included and/or studies with 16- to 24-year-olds as well. Studies that show some association or relationship between treatment adherence and psychosocial services were also included during the abstract screening.

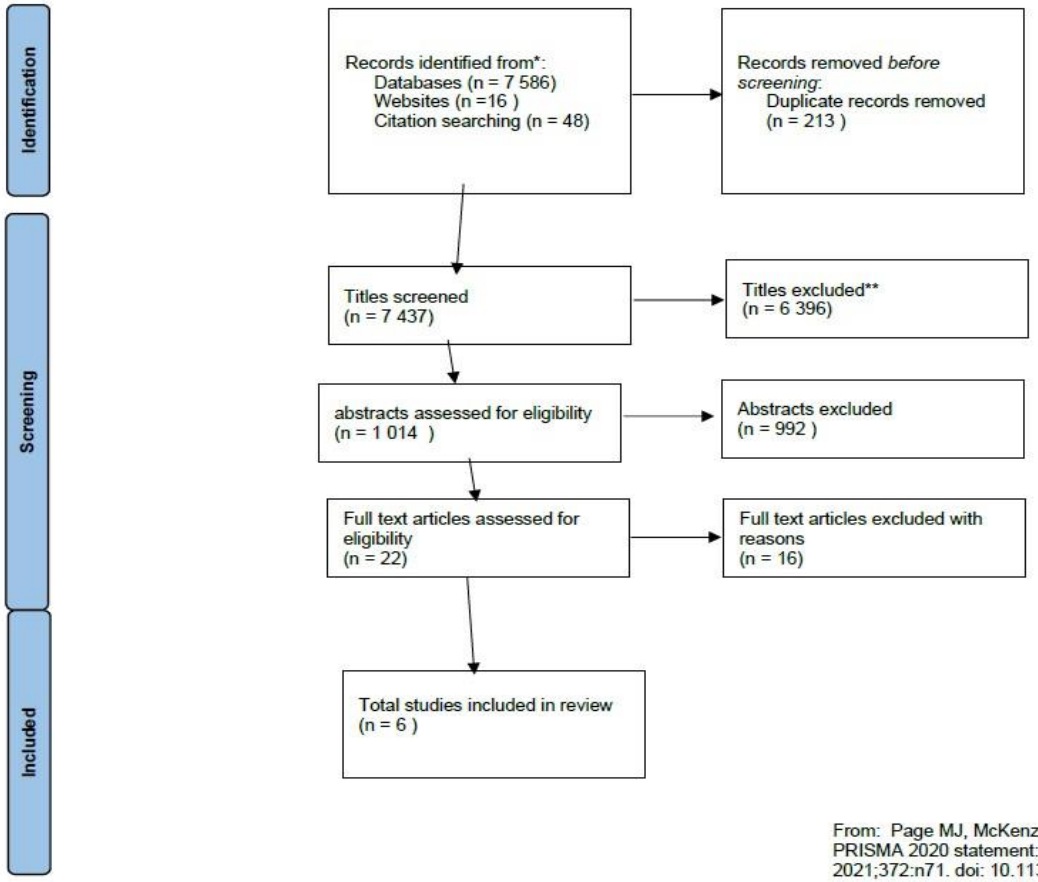
After completing the initial title and abstract screening we categorized the interventions and outcomes, a crucial step to adhering to the PRISMA guidelines. To ensure consistency on how we approach full text screening and data charting we defined our

intervention and outcome based on the abstracts we reviewed. While looking through the abstracts the primary and second reviewer noted down the kinds of psychosocial services and aspects available in LMICs. With this we also looked at how adolescent cancer treatment adherence is being defined and presented in different literature conducted in LMICs; including the different words they used to represent non-adherence to treatment. With this information we scheduled a meeting between the primary and second reviewer and talked through how we will clearly define each category of our intervention and outcome measures. This was done to ensure that our study has findings that were inclusive to our study setting while still distinct enough to facilitate meaningful discourse.

To validate the categorization of the intervention and outcome we conducted a pilot test of the first three full text articles. Through this, the primary and second reviewer were able to note all the gaps in the inclusion guide (Appendix 2) which were then adjusted as needed to increase the clarity of our findings. The adjustments were then agreed to, and the full-text article screening started.

The final inclusion guide is attached as Appendix 2 and was documented in detail to include all definitions and criteria for intervention and outcome of our study. This ensured that throughout the full text screening process, both reviewers had a guide to consistently apply the framework when extracting data from the included full text articles and any conflicts were resolved by supervisors. Ultimately the creation of the inclusion guide established integrity and transparency of our scoping review in accordance with the PRISMA guidelines ensuring that our review is replicable.

Title: Availability and Quality of Psychosocial Services for Treatment Adherence among Adolescents Living with Cancer in Low- and Middle-Income Countries: A Scoping Review



From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: http://www.prisma-statement.org/

Figure 1 Prisma Flow Diagram

See figure 1 PRISMA flow chart diagram for the breakdown of the included studies both from selected databases and other sources looked through which were reference lists, protocols, articles cited and websites, deduplicated studies, recorded papers included and excluded after title and abstract screening, recorded papers included and excluded after full text screening with corresponding reasons why in the PRISMA flow chart.

2.5. Charting the Data

For this review, our findings were charted and organized on a data extraction form (Table 2). Data extraction from the full text included articles was carried out by the primary researcher and the decisions were then reviewed by the second reviewer. If there were any conflicts, they were solved by the supervisor. Initially the following fields were included in the data extraction form: study title, publication year, study design, country of study, aim/objective of study, funding source, demographic characteristics, gap identified, psychosocial service/intervention, treatment adherence measure, study limitations, key findings, and conclusions.

A pilot test for the data extraction form was done with both reviewers to ensure the form was capturing the data in accordance with the research aim and objectives. It was important to perform a pilot test to ensure proper use and comprehensiveness during the data extraction process. The test was done with three included papers, and we found no need to include both study title and publication year and replaced these fields with a full reference. The funding source was removed because it did not add onto our findings nor answer any of our research objectives. Gap identified was also removed because research gaps are stated in the aim/objectives of the studies we included. Additionally, key findings and conclusions were grouped together because in two of the three pilot papers they were presented as a singular concept. Under the psychosocial service field, we differentiated the kinds of psychosocial services the study participants may be receiving by adding psychological support, educational support, social support (community/peer support) and complementary therapies. We employed the same strategy with the treatment adherence field and added medication/drug adherence and attendance at medical appointments.

The following are the fields used after the pilot test: full study reference, study design, country of study, aim/objective of study, demographic characteristics, psychosocial service/intervention, treatment adherence measure, study limitations, key findings/conclusions. Extracting the data through this form facilitated the collection and categorization of the findings from included studies.

Full definitions of each data field are documented in the data inclusion guide in Appendix 2.

2.6. Collating, summarizing, and reporting results

To organize and manage the extracted and charted data collected, we utilized a Microsoft Excel spreadsheet. The Excel spreadsheet ensured that the data was securely stored and easily retrievable when reporting the results. The data extraction process began with reading through the full text and identifying the main elements of our research aim, which are adolescents aged 10 to 19 years, psychosocial services provided, treatment adherence measure and the study must be set in a LMIC. These elements were then documented in the data extraction form.

During the full text data extraction process, all studies that were missing any of the aforementioned elements were excluded. The data extraction process was performed by the primary researcher and the data extracted was cross-checked by the second reviewer for quality assurance purposes. After completing the extraction, the data was synthesized; we employed a descriptive analysis method to summarize the characteristics of the full text articles included. To answer our objectives, we used the qualitative thematic analysis method to identify and analyze the primary themes and patterns found within the included studies. We then identified the psychosocialservices throughout the included studies through reviewing the data extracted. After psychosocial services were identified, we took some time to read through them and further analyze the relationships between them and their availability and quality for adolescents with cancer and treatment adherence.

The relationship between availability of psychosocial services and treatment adherence was analyzed based on the studies included in our review. We did a quick assessment of the full text articles and assessed the study objectives, study justification and problem statements to determine whether psychosocial services that

aid in adhering to treatment were available in LMICs. The primary and secondary reviewer made the choice to use these elements as the point of reference because they provide and justify the reason for conducting these studies and through them, we were able to determine whether in these LMICs there were psychosocial services present prior to these studies or not. The relationship between the quality of psychosocial services and treatment adherence was analyzed by assessing the effectiveness of the services, satisfaction of participants, and continuity and consistency of the implemented psychosocial services and or interventions in our included studies. After the full text data extraction, these three elements we identified and through them we were able to assess the effect these services had on cancer treatment adherence in LMICs. The definitions of these terms were sourced from the included studies to ensure a reliable representation of the quality of these services provided. The decision to analyze quality in this way was based on the full text literature and was approved by both reviewers. This was accompanied by a quick narrative overview assessment of the included studies to understand the scope of our review.

After completing the analysis, we presented the results in narrative and tabular format, the characteristics of selected services (Table 2: data extraction form) were presented in tabular format together with the overview of the included studies (Table 1) and the types of psychosocial services (Table 3). We went on to describe the relationship between psychosocial services and cancer treatment adherence narratively. We supported our analysis of this objective with an extensive assessment of the literature. The gaps in knowledge and areas for future research were analyzed, this involved an exploration of the limitations of the included studies which pinpointed the areas that need further research. After the results were presented by the primary researcher, they were assessed by both the second reviewer and the supervisors to assure the quality of the results.

2.7. Ethical Considerations

Due to the nature of our review only needing to collect secondary data, we were provided with an ethical waiver from the School of Public Health at The University of Witwatersrand to begin data collection.

Chapter 3: Results

A total of 7 650 records were retrieved including 7 586 from databases, 16 from websites, and 48 papers from citation searching. This data was imported into Zotero for reference management and data deduplication, 213 duplicates were removed. 7 437 remained and were imported into Rayyan for the initial title screening. After the title screening, 1 014 articles met the inclusion criteria and moved to abstract screening. After abstracts were screened only 22 papers met the inclusion criteria and 992 were excluded from the study. Of the 992 papers, most did not document a clear relationship between psychosocial services and treatment adherence or non-adherence and the papers that did were not set in LMICs according to the World Bank list as seen in the abstracts. Moreover, among the excluded papers some focused on psychosocial services to the parents, caregivers, or siblings of children with cancer but with no clear association to the adolescent going through cancer treatment, these interventions or services were measuring the parents', caregivers', or siblings' psychosocial wellbeing. After the abstract screening, six articles were included in this scoping review. Among the 16 excluded articles, one did not have a full text English version, six were not conducted in LMICs, three did not measure treatment adherence but were conducted in LMICs, one had oncology social workers as study participants, one did not define community support as a psychosocial service. The remaining four did not have enough significant information on psychosocial services provided.

3.1. Overview of Selected Studies

Six studies were included into our scoping review and the overview is presented in Table 1.

Table 1 overview of the studies included in the scoping review.

#no	Author	year	psychosocial approaches	measures of adherence	results
1	Fred M. Ssewamala, Ozge Sensoy Bahar, Kimberly J. Johnson, Ruth G.N. Katumba	2019	Cancer education for the youth and economic empowerment; to address cultural misconceptions	examine the change in cancer treatment access and adherence; this includes pill cunt, clinical appointments, prescription refill, the Morisky Medication Adherence Scale and the Brief Adherence Rating scale	N/A
2	Amaranto Suarez, Martha Piña, Diana X Nichols- Vinueza, John Edgar Lopera Marin	2015	Psychosocial support and education; provide information about ALL, the treatment and significance of adherence to the treatment regimen, reduce fear and misconceptions about cancer and to also empower families to committing to the treatment regimen.	measured treatment related mortality, therapy abandonment, event free survival with abandonment being considered an event	Significant increase in treatment related mortality and therapy abandonment from 13% to 3% and 32% to 9% respectively. Even free survival increased from 47% to 65% in 2 years. No significant improvement when it comes to even free survival, 19% in historic group and 24% in study population.
3	Shalini Jatia, Maya Prasad, Amey Paradkar, Ameeta Bhatia, Gaurav Narula,Girish Chinnaswamy,Tushar Vora, Sanjay Gomle, Hari Sankaran, Shripad Banavali	2019	Holistic support groups to provide comprehensive support, psychosocial, educational and bereavement support, weekly social tumor board meetings to create individualized support for children with cancer, counselling.	Using Time Responsive Electronic Abandonment Tracking system (TREAT) to track all children and using social workers and data managers were employed to ensure proper tracking and documentation of adherence to treatment.	annual treatment adherence rate was reduced from 20% to 3% and 6% and dropped treatment adherence from 9% to 1%.
4	Carmen Chai Wang, Lau Bee Theng, Mark Tee Kit Tsun, Abdullah Al	2022	Educational video game that uses protection Motivation theory (PMT) to motivate childhood cancer patients (CCPs) using daily self-care to boost self-efficacy,	Two protection motivation surveys and cancer knowledge surveys to measure daily self-care and treatment adherence and cancer treatment adherence.	intention to use cancer treatment increased, daily self-care intention increased, cancer knowledge increase

	Mahmud				
5	Alam Areesha,Kumar Archana	2018	social support and group counselling; divided into 4 phases from basic support and financial support	abandonment rates and refusal rates were measured using a cancer registry and follow ups on patients who refuse therapy.	Refusal of treatment reduced from 21% to 5.9%, abandonment of treatment reduced to 11.1% from 30.2%
6	Nuria Rossell, Carmen Salaverria, Angelica Hernandez, Soad Alabi, Roberto Vasquez, Miguel Bonilla, Catherine G. Lam, Raul Ribeiro & Ria Reis	2018	using local community resources to reach out to patients who have abandoned treatment and who are suspected of abandoning treatment and providing direct support.	frequency was measured of missed appointments, types of community institutions contacted to aid with families	support was provided hence reducing non-adherence and abandonment of treatment

3.1.1. Characteristics of selected studies

The characteristics of all the full text included articles are presented in Table 2 of the studies we collected. The table highlights key information based on our research aim and objectives. The studies included were conducted in Uganda, Malaysia, and El Salvador, with two studies set in India. They were collectively published after 2015, with one study being published in 2015, two studies published in 2018, two in 2019, and one in 2022. Study designs ranged from a randomized control trial design, two retrospective cohort studies, one cohort study, a mixed methods exploratory approach to a single arm single center intervention methodology.

Table 2 Data Extraction form that presents the characteristics of the included studies in the scoping review.

#no	Study Reference	study design	publication year	country	aim/objectives	sample size	study duration	demographic characteristics	intervention studied	comparison group
1	Suubi4Cancer: A protocol for an innovative combination intervention to improve access to pediatric cancer services and treatment adherence among children living with HIV/AIDS in Uganda, Contemporary Clinical Trials Communications, 2019, Vol. 16, pp.	Randomized control trial design (study protocol)	2019	Uganda	Enhance the Suubi EE intervention by including a component addressing misconceptions (in terms of beliefs, values, norms and attitudes) regarding cancer and explore the acceptability and preliminary impact of the enhanced intervention (Suubi4Cancer) on short- term outcomes, specifically: 1) change in youth and caregivers' beliefs, attitudes, and behavior to-ward cancer testing and treatment; 2) access to cancer diagnosis, care and treatment; 3) adherence to prescribed cancer care and treatment; and 4) psychosocial	78 youth aged 10 to 24 years	participants observed leading up to and for 9 months post intervention initiation	youth 10 to 24 years	The Suubi4Cancer intervention; economic empowerment and cancer education to address misconceptions about cancer	control group receives standard of care, including psychosocial counseling and basic cancer education without economic empowerment

					outcomes of youth and their caregivers. Explore multi-level factors (individual, family, cultural) impacting participation in and experiences with the Suubi4Cancer intervention (satisfaction, facilitators, barriers, recommendations).					
2	A strategy to improve treatment-related mortality and abandonment of therapy for childhood ALL in a developing country reveals the impact of treatment delays., Pediatric blood & cancer, 2015, Vol. 62 (Issue 8.0), pp. 1395-402	Cohort study	2015	Colombia	Several interventions aimed at reducing toxic deaths and abandonment were implemented, including a reduced- intensity treatment regimen and a psychosocial effort targeting abandonment. We performed a cohort study to assess impact.	Two main cohorts; the historic cohort included 181 children treated between 1995 and 2004, the study population with 99 children diagnosed and treated between 2007 and 2010 after initiation the study	1995 to 2004 and 2007 to 2010 and median follow up was 2.7 years	Patients aged 1 to 16 years old	A reduced intensity treatment regimen (LLA ACHOP 2006) and psychos ocial efforts	comparison between the historic cohort (prior interventions) and study population (post-interventions)

						interventions				
3	Holistic support coupled with prospective tracking reduces abandonment in childhood cancers: A report from India., Pediatric blood & cancer, 2019, Vol. 66 (Issue 6.0), pp. e27716	retrospective cohort study	2019	India	We describe various stages in the formation and refinement of this holistic support group (HSG) and aim to analyze the effect of this strategy on reduction of treatment adherence over time, especially in relation to the level of support available during various points of time.	11,011 children eligible for analysis between 2009 and 2016	from 2009 to 2016	All children (15 years and younger) registered in the pediatric oncology unit of our hospital were prospectively tracked as described above.	Creating pediatric cancer foundation providing holistic support (financially, lodging, educational, financial and bereavement support) and the implementation of TREAT (Time Responsive Electronic Abandonment Tracking system for tracking.	comparison between rates of treatment abandonment across years between 2009 to 2016, comparing before and after the implementation of the holistic support approach and TREAT system

4	Increasing motivation for cancer treatment adherence in children through a mobile educational game: a pilot study, EAI Endorsed Transactions on Pervasive Health and Technology, 2022, Vol. 8 (Issue 30.0), pp. e4--e4	single arm single center intervention design	2022	Malaysia	This pilot study aims to assess and explore the effectiveness of a serious game intervention to motivate children with cancer to adhere to their treatment, encourage daily self-care, and educate them about cancer and cancer treatment.	8 child cancer patients	one month	6-17 years old	Virtual pet mobile game called "Pets vs Onco" created to motivate children to adhere to cancer treatment while managing their treatment side effects using self-care.	N/A

3.1.2. Psychosocial Services for adolescents with cancer in LMICs

Our preliminary research pointed us towards vast psychosocial services being provided in LMICs for adolescent cancer patients that will be discussed in more detail in the discussion section of our paper. Table 3 describes the characteristics of the psychosocial services reported in the papers included in the review.

Table 3 : Describes the psychosocial services included in the review, these services are broken down into three types; psychological services, educational services, and community services.

Psychosocial Service Type	**Description**
Psychological support	● Basic counselling by volunteers (58) ● Support from psychologists and psychiatry professionals to provide support to families that are suspected of abandoning treatment (59) ● Individual counselling by pediatric psychologists, volunteers, and social workers (59) ● Individualized holistic support: counselling for motivation of children/families and counselling on medication compliance (58)
Educational support	● Cancer specific education sessions on cultural explanations on causes and misconceptions of cancer (beliefs, norms, attitudes, and values) (60) ● Educational video game named “Pets vs Onco” with an educational module that is a collection of easy to understand information on cancer, its treatment and self-care skills to manage treatment effects (61) ● Parent education: family counselling sessions on cancer curability, treatment, treatment related complications and how to prevent them at diagnosis (62) ● Education support: continuing education or patients with cancer through formal and informal programs to ensure education is not compromised during in-patient treatment (58)
Community support	● Parent Support group: quarterly group counselling for families to aid in solving their questions on cancer and survivor stories were shared and celebrated in this program (advanced to a monthly basis: stories of child cancer treatment abandonment were shared with relapsed children that are on-treatment) (58)

	● Contacting local community institutions when a child misses an appointment for a prompt location (63) ● Home visits: community persons visit the families at their home to help encourage them to return to the hospital (63).

As shown in table 3, psychosocial services included in this study ranged between psychological support, educational support, and social support which included community. two out of six studies looked at psychological support alone and three out of six other studies looked at both psychological and educational support. Lastly, one study looked at group counselling as both a psychological and community support measure.

3.1.2.1. Psychological services

Psychological services were presented in different ways in our included articles; through group counselling, individualized holistic support plans, and individualized counselling sessions for adolescents with cancer (58,60-62). Among these, there were interventions that focused on changing adolescent and caregivers' beliefs, behaviors and attitudes towards cancer testing and treatment (60). There was also a focus on improving self-efficacy and social support which inadvertently increased access to cancer treatment services of families of adolescents with cancer (61). Cultural misconceptions were also addressed as a key element, and this was done through cancer education sessions (60). Among the included studies, one paper set in India was successful in reducing treatment adherence significantly over time through counselling that emphasized the significance of adherence (62). Treatment abandonment reduced from 30.2% to 20.3% from phase one of the intervention and this change was notably higher when focused counselling groups were introduced later on in the study (62). Through holistic support, another intervention noted the annual rate of cancer treatment abandonment decreased from 20% in 2009 tobetween 3% and 6% from 2012 to 2016 (58). Initially, this decrease was noted after the introduction of limited emotional support and counselling between 2010 and 2011and it lowered again after introducing holistic support in this intervention (58).

It is important to note that some of these psychological interventions were accompanied with financial support, literacy, and economic empowerment (60-62).

However, our findings show that to ensure a sustainable cancer treatment journey for the adolescent cancer patient, psychological support needs to be a key element in these interventions.

3.1.2.2. Educational services

Educational support was provided through cancer specific education sessions, education video games, parent education and formal and informal educational programs (58,61). The educational support programs were used to teach about cancer services, cancer treatment, the importance of adherence to cancer treatment, self-care and in one intervention they were used to bring education closer to the adolescent cancer patients through integrating school programs in the health care facilities (58, 61-62). The educational mobile game named Pets vs Onco had a direct effect on treatment adherence on adolescents in Malaysia (61). This game focused on encouraging childhood cancer patients to adhere to treatment and daily self-care through the combination of education and gameplay (61). The game was consistently played by the participants during the time of the intervention, most playing daily, one playing once a month and two playing a couple times a week. It directly contributed to the increase in adherence through engaging their adolescent audience with fun and interactive ways to learn about cancer while increasing motivation and self-care practices (61). Among eight of the participants that answered the feedback survey; six agreed to the positive effect it had on daily self-care and treatment adherence (61).

Including educational support by implementing formal and informal education programs was part of a holistic approach intervention in one of the included studies in India (58). Through introducing these specific educational programs, it ensured the adolescent's educational needs were consistently met, reducing their fear of failing and falling behind with their classes bringing forth a sense of normalcy (65). Implementing these holistic measures reduced treatment non-adherence significantly among the study participants (58). Additionally, this program was created to seamlessly integrate into the in-patient and out-patient pediatric oncology units at the Tata Memorial Hospital in Mumbai (58). Showing the significance of educational services and support being provided to combat adherence issues in adolescents with cancer in LMICs.

3.1.2.3. Community services (support groups)

Community services and support was shown through community mobilization and support groups such as a parent support groups, home visits, and engaging the local community organizations to aid whenever a child misses their appointments at the hospital (58,63). One study showed that overall community support was available throughout the adolescent's treatment regime from time of diagnosis (58). However, it is important to note that treatment adherence after the start of cancer treatment started increasing only after the implementation of the Parent Support Group program. This reduction was reported in both the adolescents and their parents and caregivers from 9% in 2009 to 1% in 2016 (58). Another study in included in our review investigated home visits and engaging with local community institutions and found similar effects to treatment adherence measures (63). Home visits were made when children missed their hospital appointments and when families were suspected of abandoning treatment due to socioeconomic determinants (63).

These programs were facilitated by the Pediatric Cancer Foundation in India, several hospital team members (social workers, pediatric oncologists and volunteers), local non-governmental organizations, municipalities, health units and a church (58,63).

3.1.3 Relationship between psychosocial services and treatment adherence in adolescents in LMICs

3.1.3.1. Cancer treatment adherence in adolescents in LMICs

The definition of adherence was consistent throughout the whole scope of our included studies. It was measured using cohort-based measures, surveys based on the motivation theories, over a period of time, and through systematic tracking systems (58-61,63). Cultural misconceptions about cancer, gender biases, side effects of treatment, untrue beliefs on cancer treatment toxicity and curability, preferring the use of traditional medicines, inadequate resources and financial barriers were the factors that influence adherence according to our review findings (58). These factors were a cause for abandonment of cancer treatment not only within the adolescent population, but they also influenced parents and caregivers of adolescent cancer patients. Jatia et al (2019), found poor supportive care, false diagnosis and inadequate pediatric cancer units to challenge cancer treatment adherence rates in LMICs (58).

Three papers from our included studies indicate that reduced treatment adherence and abandonment is probable especially when services, interventions or programs are integrated with psychosocial factors. In one paper, providing psychological, educational and community support to the adolescent population played a significant role in ensuring adherence is sustainably maintained. Group counselling reduced cancer treatment adherence from 21.02% to 5.9% in a couple of years (69). Our study also reveals the effectiveness of educational programs like Pets vs Onco, in the increase of treatment adherence among adolescent cancer patients (61). Adolescents and caregivers of the adolescent participant reported the significance and improvement this mobile game app has shown on adhering to treatment and selfcare regimes that aid in the treatment regime (61). Jatia et al's (2019) paper also shows a clear connection between treatment abandonment among pediatric cancer patients in India and community support groups. With the implementation of this program the annual rate of treatment abandonment decreased to 3% and 6% respectively from 20% in a span of eight years (58).

3.1.3.2. Psychosocial service availability and quality and its relationship with cancer treatment adherence

Suarez et al demonstrated the lack of psychosocial services in LMICs and when compared to HICs the disparity on availability and quality of these services for adolescents with cancer was staggering (59). Adolescents in LMICs needpsychosocial services due to the psychological and social issues they are susceptibleto facing during the course of their cancer treatment (59).

3.1.3.2.1. Relationship between availability of psychosocial services and adolescent cancer treatment adherence in LMICs

Here we explore the relationship between the availability of psychosocial services for adolescents in LMICs and cancer treatment adherence. Our results showed the lack of psychosocial services provided to adolescents with cancer in LMICs to support treatment adherence.

Our scoping review recorded only six papers set in LMICs that investigated the relationship between psychological, educational and community services and adolescent cancer treatment adherence. Findings show that in Uganda there are no recorded community level efforts that improve adherence to treatment among

disadvantaged populations (60). Similarly, in India, reports show no substantial information on the impact of interventions that focus on treatment abandonment (62). Nuria et al also found that in El Salvador, holistic strategies that bring together diverse local institutions or resources in LMICs to create psychosocial programs and services are not well developed or recorded (63). Hence increasing difficulties in creating comparable discourse on the present programs, hindering the overall creation of these psychosocial services (63).

Limited availability of psychosocial services in LMICs is disadvantageous to adolescents going through cancer treatment. This is evident in one included study in India where prior to the introduction of parent support groups, the rate of abandonment of adolescent cancer treatment was 37.1% (62). This decreased with the introduction of this support group to 10% (62). Moreover, another included study found that the implementation of a well-rounded psychosocial intervention that addressed the cancer patients' emotional impact of a cancer diagnosis to families of adolescents aged one to 16 years significantly decreased treatment abandonment to 9% from 32% (59). This was done through actively engaging with social workers and mental health professionals, prompt support to families suspected of abandoning treatment through counselling and psychological and psychiatry support to reduce emotional distress and increase knowledge on the significance of acute lymphoblastic leukemia treatment for survival (59).

3.1.3.2.2. Relationship between quality of psychosocial services and adolescent cancer treatment adherence in LMICs

The quality of psychosocial services was not directly measured in the included studies; however, quality was still assessed through investigating the effectiveness of the services, satisfaction of participants, and continuity and consistency of the implemented psychosocial services and or interventions.

In two of the included studies, effectiveness of psychosocial services was measured using a tracking system named Time-Responsive Electronic Abandonment Tracking (TREAT), group efforts such as tracking through telephones, communication through pre-paid postcards, and home visits from the foundation providing the service and through a prospective cohort study of 22 years (58,62). Through these measures we were able to identify the quality of these services by looking at the definition of service effectiveness used in these papers and compare it to the effect these services had on

their desired outcome (treatment adherence) (58,62). The definition of effectiveness was consistent between these two studies; it was defined as the rate of change or reduction in treatment abandonment and treatment refusal among children with cancer (8,2). Both studies presented significant effectiveness through low rates of treatment non-adherence; from 20% to 6% and 30.2% to 11.1% respectively (58,62).

We included participant satisfaction as a measure of quality of psychosocial services in our review, in one of our included studies participant satisfactions was defined as the level of participation, usefulness, enjoyment and the impact the educational game had on its proposed outcomes (treatment adherence, daily self-care and knowledge on cancer treatment) (61). They used a survey and questionnaire to measure the adolescent's satisfaction on an educational mobile game (61). The survey and follow up questions asked the adolescents and caregivers to provide general feedback on usability and the content presented in the game. This survey was done at the end of the intervention, and it showed that the game was positively received by the adolescents (61). Using a scale of 1 to 5, 1 being strongly dislike and 5 being strongly like, three out of eight participants strongly liked the game rating it at a 5, two liked the game, two felt neutral to the game and one strongly disliked the game (61). With the younger participants in the group enjoying the game much more in comparison to the older participants (61). Additionally, the questionnaire presented to the caregivers showed a positive relationship between the game, treatment adherence and self-care for adolescents with cancer in LMICs (61).

We included consistency and continuity of the intervention or service as a measure of quality psychosocial services in LMICs among adolescents with cancer. This demonstrated the relationship between quality of psychosocial services and cancer treatment adherence because adherence can be simply defined as consistent use and application of treatment measures. Jaita et al's (2019) study showed consistency through the provision of constant holistic support and the implementation of a tracking system to ensure continuity of the services was well documented (58). The continuous provision of these services significantly improved the annual rate of cancer treatment abandonment, this change was evident in the reduced rate of treatment abandonment (20% to 6%) after continuous implementation from 2009 to 2016 (58).

We integrated participant satisfaction, consistency and continuity and effectiveness to measure quality of the psychosocial services included in our review. Using this method, we described the effect that these services had on treatment adherence in LMICs.

3.1.4. Gaps in research on Psychosocial services that influence cancer treatment adherence in adolescents living in LMICs

Our findings presented areas for improvement in research and overall implementation and creation of psychosocial services that increase adolescent cancer treatment adherence in LMICs. Our scoping review included only six papers which clearly indicates the gap in research on psychosocial services that affect treatment adherence in underdeveloped nations. Moreover, studies need to put more focus on investigating the effects of psychosocial services on adolescents aged 10 to 19 years in LMICs. Our findings were a variation of studies focusing on children, adolescents and young adults aged one to 24 years old (58-63). This is crucial due to the disparities in the needs of adolescent cancer patients in comparison to children and young adults.

The implementation of long-term psychosocial services should be a priority because most adolescent cancer treatment regimens can take up to two years. One included study was a retrospective cohort study. Using this design the researchers were able to capture the gradual increase and changes in treatment adherence among children aged 18 years and younger (62). The adaptation of long-term psychosocial services for adolescents with cancer to fit their long-term treatment regimens should be prioritized to ensure continuity and consistency hence maintaining high rates of treatment adherence throughout (58). Furthermore, among the included studies two papers were limited by their small sample sizes. For future studies, generalizability needs to be prioritized to ensure the psychosocial services created can be implemented in vast adolescent cancer centers in LMICs (62-63). More sustainable adolescent cancer treatment adherence tracking systems need to be investigated for implementation in LMICs (58). The reliability of tracking systems like TREAT needs to be researched in several LMICs due to how simple it is to use; how accessible it is and its low cost (58).

Chapter 4: Discussion

This scoping review aimed to describe the psychosocial services that are available for adolescents living with cancer, the relationship between the availability and quality of these services on treatment adherence among adolescents in LMICs and the gaps in literature on the psychosocial services that aid in treatment adherence among adolescents with cancer in LMICs. Our findings showed evidence of the relationship between psychosocial services and treatment adherence among adolescents with cancer in LMICs. We found a clear association between psychological, educational and community services and treatment adherence for adolescents with cancer in LMICs.

4.1. Overview of included studies

The included studies were conducted between the years 2015 to 2022 highlighting the recent need for filling the gap that was perpetuated by treatment adherence among adolescents and the psychosocial services that can impact its change. Moreover, there were two retrospective cohort studies; one lasted 22 years with recent adaptations of psychosocial services being introduced 14 years into the study and the second one lasting seven years with adaptations being made as prospectively whenever issues that hindered adherence to treatment arose among the study population (62). Apart from these retrospective studies, study designs included in this review ranged from randomized control trials (RCTs), cohort study, a single arm single center intervention study, to a mixed methods exploratory study (58-61,63). This variation in study designs demonstrated a range of evidence that presented a holistic view of our research aim, it provided high quality evidence on the intervention outcomes from the RCTs, gave a direct look and assessment of the psychosocial intervention's impact on treatment adherence and cancer mortality for adolescents in the study (58-61,63). The retrospective cohort studies provided a clear look at the long-term trends on treatment adherence and the effects psychosocial interventions may have on the outcomes over time (58,62). The mixed methods exploratory research design provided the researchers with a wide breadth of data collection tools that resulted in acquiring the best qualitative insights from families and adolescents with cancer (63). For future implementations of similar psychosocial services and programs, this study's findings will aid in tackling the

challenges families of children with cancer face to ensure maintenance of treatment throughout their regime (63). The single arm single center study was chosen due to its ability to provide a focused view on the intervention and to pilot the mobile educational game to test its reliability, replicability, and usability prior to implementation to a wider audience (61). The use of pre and post-test surveys provided the researchers with a statistical measure of the impact on adherence to treatment but also a more personalized view of the impact the mobile game app had on treatment adherence was acquired from the qualitative approach (61). For future implementation of similar apps in LMICs, these results will aid in providing the best experience for future adolescent cancer patient users.

As noted in the data extraction form, our scoping review comprised studies set in LMICs from various parts of the world including Uganda, Colombia, two studies from India, Malaysia and El Salvador (58-63). Spread across different continents of the world, these inclusions provided a variant look at the kinds of psychosocial services that work best in different regions of the world and how they address adherence to cancer treatment in adolescents. It is important to note the kinds of services implemented in each country and their effect on adherence to treatment and if they are replicable to other LMICs. Despite all the included studies being in LMICs some of the interventions implemented may be hard to replicate in other regions. A good example is the mobile video game educational app, for this study, participants had to have an android mobile device which may not be the case for some adolescents in Uganda, El Salvador, or any other very low-income country according to the World Bank list. Additionally, it is also crucial to note the kinds of interventions implemented in the poorest countries included in our review in comparison to others. In El Salvador and Uganda, economic support was essential, and it was accompanied by community and educational based services (60,63). Similarly, in Colombia and Malaysia where the GDP is higher the same types of services were implemented (59,61). Furthermore, in India psychological services were at the forefront of both studies (60,62). Looking at these variations may depict the best kinds of psychosocial services that can bring forth the best treatment adherence measures for these regions.

The studies sampled adolescents and children with cancer from age one to 24 years old, similarly to the demographic characteristics of the study participants in the

studies. Among the included studies, only one study disaggregated between aged groups when measuring their findings. Through employing surveys and questionnaires to measure the impact of a mobile educational game on treatment adherence, they found younger adolescents to enjoy the game more than older adolescents (61). Specifics in age were not exclusively made in their findings (61). Evidently, the psychosocial needs of adolescents with cancer may be very different to children and young adults. This portrays the need for research on psychosocial needs of adolescent aged 10 to 19 years with cancer as they experience cancer, psychological and social services very differently from children aged one to nine years and young adults aged 20 to 24 years.

4.2. Characteristics of adolescent psychosocial services in LMICs

In LMICs, psychosocial services that target treatment adherence among adolescents are scarce and the present services are accompanied by economic or medical factors. Among our included studies some have an economic component attached to them. Elements such as financial literacy, economic empowerment, and financial support were at the forefront of some of the interventions (58,60). This is may be due to a combination of limited resources and high costs of cancer care in LMICs; research shows LMICs only having allocated 5% of the global cancer care resources at their disposal (59). This puts a strain in the cancer care and support systems and prevents the implementation of the best kind of cancer care services for disadvantaged and unique populations like adolescents (59). This is not to show that psychosocial services are not important, evidently the studies that combine psychosocial services with financial support systems show consistent increase in the adherence measures in comparison to those with only financial support (58).

Educational services were found to be effective when promoting and encouraging adolescents to adhere to treatment in LMICs. Ongoing educational support for in and outpatient adolescent cancer patients was an educational intervention that contributed to the increase in treatment adherence among adolescents (58). During this pivotal and difficult time in the adolescent's life, it is crucial for adolescents to engage in normal day to day activities just like their peers (58). Especially for hospitals without schools on the premises, organizations like The Childhood Cancer Foundation South

Africa (CHOC) provides an interactive learning experience that aims to improve patient skills while encouraging educational development (64). Provision of these services encourages treatment adherence because normalcy increase adolescent quality of life and desire to reach survivorship which in turn motivates adherence to cancer treatment (64). Educational video games such as the “Pets vs Onco” mobile game that provides easy to understand cancer education and treatment adherence motivation for adolescents with cancer, significantly improved adherence among their study population (61). However, implementing this kind of program in LMICs can be difficult due to limited access to android mobile devices or any kind of technological devices in these low-income regions. Moreover, cancer specific education sessions that focus on interpreting the cultural misconceptions of cancer were effective in reducing treatment adherence in LMICs (60). This is due to the lack of knowledge on treatment and its effects among families with children that have cancer and the stigma that surrounds the disease.

Cultural misconceptions are a cause for stigma and a barrier to adherence among parents of adolescent cancer patients (60). Parents are responsible for their adolescent’s treatment plan and ensuring the child sticks to their treatment regime. Employing educational services that cater to promoting the understanding of the significance of adhering to treatment and its effects when not adhered to such as toxicity, relapses and deaths encourages the parents to push for the adherence to their children’s cancer treatment regime (65). In some LMICs, communities in parent’ssocial groups have identified cancer as a curse or punishment for sins (65). Community members’ opinion such as child being bewitched and encouragement to seek alternative treatment and stop the present medical treatment were noted as barriers to treatment adherence (65). Demonstrating the need for community-based interventions and support groups to ensure caregivers of children with cancer are surrounded by peers who are or have had similar experiences. Additionally, the parents also reported opinions and advice from peers with children going through cancer influencing their perception of the effectiveness of cancer treatment (65). This shows the significance of incorporating parents and caregivers into the psychosocial support systems that aid their children to adhere to treatment, especially educational services.

Community services and support was a way to empower parents of children with cancer and children themselves to adhere to treatment. Our study found that social support, group counselling and involving local organizations and communities were the important ways to reach adolescents who are not adhering to cancer treatment. Families of adolescents who are going through cancer that were suspected of non-adherence were contacted and through home visits and support by volunteers discovered reasons for treatment abandonment (63). Measures were then taken to assure these families are back on treatment using NGOs, local municipalities, and churches (63). Furthermore, building supportive communities can also be seen in various LMICs, like in Zambia where organizations like The Zambian Childhood Cancer Foundation (ZACCAF) were created by parents who have directly experienced the effects a cancer diagnosis and the disease can have on children and parents. Through its mission ZACCAF has been able to provide active support to families that have children going through cancer treatment (66). Interventions and services like these need to be adapted to measure cancer treatment adherence to ensure it is maintained in LMICs. With cultural misconceptions and pressure from extended families to stop treatment, involving parents as stakeholders in the creation and implementation of programs like these will create environments where peers interact and gain positive insights that will aid in decreasing non-adherence among adolescent cancer patients in LMICs (60).

Psychological services were also found to be effective in aiding adherence to treatment in LMICs. The implementation of programs and services that aid in changing the beliefs, fostering self-efficacy, behaviors, and attitudes of adolescents towards cancer testing and treatment recorded a reduction in treatment adherence exponentially. Counselling services and holistic support in LMICs were recorded to have an impact on both treatment refusal and adherence in adolescents (60). Our findings indicated the high levels of change in cancer treatment refusal and adherence when services that support adolescents psychologically were introduced into present interventions. Introducing and adapting psychological interventions that tackle issues like depression, anxiety, low self-esteem, and others, directly aid in the reduction of adherence to treatment as shown in our findings. CHOC is a good example of an organization that provides professional and non-professional emotional support to adolescents and children suffering from cancer. Support is mostly provided through

survivor groups, parent support groups, volunteers supporting adolescent patients and parents alike (67). All these are present in Pediatric Oncology units in different hospitals in South Africa such as the Charlotte Maxeke Johannesburg Academic Hospital (CMJAH) (67). Additionally, a gap needs to be filled with more psychological services that specifically cater to the increase of treatment adherence among adolescents aged 10 to 19 years through the maintenance of their psychological state.

4.3. Relationship between psychosocial services and adherence for adolescent with cancer in LMICs

The lack of research on psychosocial services that aid in treatment adherence among adolescents with cancer is evident in our research findings. Our scoping review included only six studies that have measured the relationship between cancer treatment adherence among adolescents with psychosocial services. Clearly demonstrating the unavailability of psychosocial services that have not been evaluated or proven for their impact on treatment adherence among adolescents with cancer. It is important that more research is conducted to demonstrate this as there is potential for improved health outcomes and survival from adolescents with cancer if these services are well supported. During the course of treatment, adolescents experience vast number of issues that may deter them from continuing with treatment. Issues such as low self-esteem, fear of being left behind, depression, stigma, anxiety, fear of relapse and death (68). Our findings show that if not addressed in the right manner, these factors will perpetuate non-adherence in adolescents with cancer.

The need to employ quality and available psychosocial services for adolescents is more prominent in LMICs due to the high rates of adolescent cancer treatment abandonment in this region. Upwards of 80% of children and adolescents diagnosed with cancer in HICs go into full remission while only 30% of adolescents diagnosed with cancer in LMICs can go into remission (61). This disparity is staggering which is why it is important to adapt and implement high quality psychosocial services in LMICs. We looked at consistency and continuity, participant satisfaction and effectiveness to determine the quality of psychosocial services in LMICs. These factors are what should be used in creating future psychosocial services for adolescentcancer patients because of the impact they have when either one is not integrated into

a service or intervention. This is because poor quality psychosocial services lead to poor outcomes.

In LMICs, financial barriers are key to limited access to treatment and treatment adherence. Rossell et al identified heavy financial burdens as a barrier to treatment adherence in adolescents going through cancer in El Salvador (63). This study also pointed out that governmental organizations do not provide financial assistance of any kind for long term treatment in governmental health care institutions. This barrier to health care services was recorded to be a cause for most adolescent cancer treatment abandonment due to the long-term treatment regimens needed to cure most adolescent cancers (63). The provision of direct financial support was noted in a similar study, this support was provided to aid in the acquiring of medication drugs hence increasing adherence to cancer treatment for these adolescents (62). This demonstrated the significance of interventions that provide economic empowerment and create financial support systems that address financial constraints as presented in some of the studies included in our review (60,62). Two studies in our review identified costs of travel to and from the hospital and cancer care centers as a barrier to treatment adherence (62). This was addressed through aid in transporting children and adolescents with cancer to their appointments and provision of accommodation for families of adolescents with cancer that is closer to the hospital. Having a full scope of these barriers will inform research and policies to ensure they are not only addressing psychological barriers but including socioeconomic barriers in these interventions as well. This is because in most LMICs only addressing psychological barriers and not including financial and geographical barriers may not be sufficient in reducing non-adherence to adolescent cancer treatment.

4.4. Limitations

Not including and using specific cancer names that affect our target population was a limitation when it came to data collection. Including leukemia, Hodgkin's lymphoma and any other adolescent cancers in our search strings may have broadened our search. Another limitation was using the World Bank list of LMICs, using this list enabled a broad search on the psychosocial services present in this region however this list changes in accordance with the GDP (69). We began our data search in 2023 and the data was reported in 2024, in this list there are some nations that were in the LMICs category that are presently not included in this list. This reduced the number of included studies in our review. Using Cochrane as a search database was a limitation as its library comprises of more randomized control trials and quasi experimental studies than intervention studies. Not using PsycINFO as a search database limited the interventions we found as its library comprises of vast psychosocial studies and interventions.

Additionally, excluding papers not written in English placed a limit on the numbers of papers we included in our review. This affected comprehensiveness of our review as a scoping review maps out the literature existingand this limitation caused us to set aside literature that may have added to the insightsto our research topic. The quality of psychosocial services was not measured in any of the included studies, this limited our ability to provide comprehensive discourse in our findings on the quality of the psychosocial services in the LMICs. Additionally, ourincluded studies not measuring quality of the presented psychosocial services limited our review from having an authentic depiction of the quality of presented services fromthe research included in our review.

Chapter 5: Conclusion and recommendations

5.1. Conclusion

The impact of availability and quality of psychosocial services and treatment adherence among adolescents with cancer in LMICs was investigated. Through our review we determined that available and high-quality psychosocial services among adolescents increases treatment adherence among this population in the LMICs regions. Availability and quality of psychosocial services for adolescents with cancer in LMICs is very low. In spite of this observation we found that overall, the presence if sustainable and consistent psychosocial service aids in maintaining treatment adherence for adolescents with cancer in LMICs. There still needs to be more research on the quality of psychosocial servicesand how that may affect cancer treatment adherence in developing countries.

Our findings clearly reflect the gap in research on the relationship between psychosocial services and treatment adherence in adolescents with cancer living in LMICs. Despite this, our review identified services that support adolescents psychologically and socially through psychological therapies, education, and community support. Our research findings can be used to implement the best kinds of psychosocial services to tackle treatment non-adherence to adolescents with cancer in LMICs.

Our methodology can also be used to replicate similar studies and measure the relationship between treatment adherence and the psychosocial services presently functioning in LMICs. Using a scoping review aided in the mapping of existing literature on our research aim which is essential to paving way for more research that investigates the availability and quality of psychosocial services and how they affect treatment adherence in adolescent cancer patients in LMICs. Additionally, the literature mapped in this review can act as a foundation to the creation of primary data studies that can help investigate long term outcomes of psychosocial services on adolescent cancer treatment adherence in LMICs. This will enable changes and adaptations in health policies to ensure quality psychosocial services for adolescents with cancer are available to all affected with cancer aged 10 to 19 years old.

5.2. Recommendations

Research on adolescents aged 10 to 19 years old should be a priority, especially in LMICs. With the steady increase in adolescent cancer mortality rates in LMICs, the need to investigate this specific age group due to their particular needs should be placed at the fore front. This review also presents a need for collaborative efforts and interdisciplinary research on psychosocial services on adolescent cancer patients in LMICs. Collaborations between cancer research, psychological research and social services need to be initiated to enable the creation of innovative services that can improve adolescent cancer treatment adherence, and the care needed to sustainably maintain adherence.

The need for more accessible psychosocial services for adolescents going through cancer is crucial and needs to be investigated. Research specifically focusing on creating availability for these services needs to be prioritized especially currently. It is also important to note the variations of need in different regions of LMICs, through our review we found disparities in availability and accessibility of psychosocial services that may bring changes in adherence to treatment among adolescents. During the implementation of these services this, major focus needs to be placed here because online psychosocial services may not be feasible in very low-income regions unlike middle income regions.

Evidence from our review did not demonstrate the effects adolescent peer support groups had on treatment adherence due to the present gap in research. However, organizations like Love Your Nuts (South Africa) are a great example of community and peer support programs that can be adapted to also measure adherence of treatment due to the success it had on encouraging adolescent boys to test for testicular cancer (70). Through testimonials we discovered that this organization curated a space for adolescent boys to speak freely and openly about their struggles with testicular cancer through WhatsApp hence encouraging others to do the same. Their Facebook page, website and video clips are shown to aid in early detection hence reducing chances of chemotherapy increasing survivorship. Making this the perfect psychosocial service and intervention for adolescents with cancer in some middle-income countries (70).

Due to the need for psychosocial services that aid in treatment adherence for adolescents with cancer in LMICs, the present psychological or social programs and services in oncology centers should be investigated. Their effectiveness or potential efficiency on impacting treatment adherence amongst this population needs to be tested. If proven useful, these services should be adapted to fit the needed criteria and used to ensure treatment adherence among adolescents living with cancer.

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APPENDIX 1: Plagiarism Declaration Report

PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

SENATE PLAGIARISM POLICY: APPENDIX ONE

I INNOCENSIA COLUMBA KAMBEWE (Student number: 1505689

) am a student registered for the

degree of MASTERS IN PUBLIC HEALTH in the academic year 2024.

I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others. - I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.
- I have included as an appendix a report from "Turnitin" (or other approved plagiarism detection) software indicating the level of plagiarism in my research document.

Signature: Date: 30/03/2024

APPENDIX 2: Full Inclusion guidelines

Here we provide a clear criteria and guide used to categorize psychosocial services and treatment adherence in our review when full text article screening.

Inclusion Criteria:

The inclusion criteria will be:

- All studies directly address interventions done and created for adolescents.
- Services or interventions designed to provide adolescents with cancer, psychological, spiritual and emotional guidance such as counseling, coping strategies, problem solving therapies, cognitive-behavioral therapy, motivation, and stress managingtechniques.
- Educational programs for adolescents with cancer, that are community based and based on psychological or social aspects described to affect adherence to cancer treatment in LMICs. These psychological and social aspects include depression, anxiety, self-efficacy, self-esteem, stigma, fear of death, dependence from family, lackin independence,
- Community and peer support programs for adolescents with cancer, that showcase community and support between adolescent cancer patients themselves or between adolescent cancer patients and heath care professionals (hcps) and that have showna positive relationship between the program, service or intervention and cancer treatment adherence LMICs.
- Complementary therapies for adolescents with cancer, such as Meditation, yoga, guided imagery, breathing exercises, stress reduction based on mindfulness, art, and music therapy based on aiding the reduction in psychological and social issues that affect treatment adherence among adolescents with cancer in LMICs.
- Studies that measure or use the following:
    - Chemotherapy sessions attendance
    - Medical and drug adherence such as oral medication adherence or oral chemotherapy adherence
    - Nonadherence
    - Inconsistencies in cancer treatment

- Ability to adhere to treatment
- Abandonment of cancer treatment
- Treatment abandonment
- Adhering to treatment plans
- Treatment compliance
- Follow up visit counts
- Comply with treatment

Study delivery mode: Any form of delivery should be included; in-person, online or digital platforms, group and individual sessions.

Only include studies on parents if the intervention's outcome presentedmeasures the child's cancer treatment adherence and clearly states how the psychosocial intervention for parents has actively affected treatment adherence of adolescent cancer patients aged 10 to 19 years in LMICs.

Exclusion Criteria:

- articles not in LMICs according to the World bank list
- studies targeting adult cancer patients,
- studies targeting or measuring treatment adherence of anyone other than adolescents
- studies targeting or measuring psychosocial services used by anyone other than adolescents
- non-English papers without translation,
- studies not focusing on psychosocial services as mentioned above
- studies not measuring treatment adherence of adolescent cancer patients

APPENDIX 3: ETHICS WAIVER

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG	HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

Office of the Deputy Vice-Chancellor (Research & Innovation)

TO: Ms I Kambewe
School: Public Health
Department:
Division:
Medical School
University
E-mail: 1505689@students.wits.ac.za

CC: Supervisor: Professor N Christofides Nicola.Christofides@wits.ac.za
and <HREC-Medical.ResearchOffice@wits.ac.za>

FROM: Mr Iain Burns
Human Research Ethics Committee (Medical)
Tel: 011 717 1252

E-mail: Iain.Burns@wits.ac.za

DATE: 27/11/2023

REF: *R14/49*

PROTOCOL NO: W-MvN-231127-01 (This is your ethics application study reference number. Please quote this reference number in all correspondence relating to this study)

PROJECT TITLE: *Impact of availabilty and quality of psychsocial services on treatment adherence amongst adolescents living with cancer in low to middle income countries: a scoping review*

Please find attached the Ethics Waiver Certificate for the above project. I hope it goes well and that an article in a recognized publication comes out of it. This will reflect well on your professional standing and contribute to the Government funding of the University.

MSWorks2000/Iain0007/ClearScanWaiver.wps

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG	HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

Office of the Deputy Vice-Chancellor (Research & Innovation)

27/11/2023

Ref: W-MvN-231127-01

TO WHOM IT MAY CONCERN

Waiver: This certifies that the following research does not require clearance from the Human Research Ethics Committee (Medical)

Investigator: Ms I Kambewe
Student No. (if appropriate): 1505689
Staff No. (if appropriate):

Supervisor: Professor N Christofides

School: Public Health
Department:
Division:
Medical School
University

Project title: *Impact of availabilty and quality of psychsocial services on treatment adherence amongst adolescents living with cancer in low to middle income countries: a scoping review*

Reason: Review of information in the public domain
No human participants will be involved in the study

Ms M van Niekerk
Co-Chairperson: Human Research Ethics Committee (Medical)

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