Systematic Review of available psychosocial support for pediatric oncology patients in nations with Universal Healthcare Coverage

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1.0 Introduction

Global health, a field of study promoting health for all, draws attention to the environmental, economic and social factors that underlie health inequities. Increasing acknowledgement of global health in the healthcare sector has led psychosocial wellness to be recognized as a major source of patient wellbeing. The COVID-19 pandemic, the increasing influence of social media and other recent issues have reinforced the need for psychosocial support.

For patients with complex illness like cancer, periodic psychosocial support is a vital source of wellbeing. Cancer is further complicated in paediatric patients due to their stage of physiological development, chances of developmental and social disruption due to intensive treatment procedures, lack of involvement of children in decision-making and more (Hasan et al, 2021). These unique factors necessitate recognition by healthcare systems (Federico, Brennan, and Dyer 2011). Addressing patients' psychosocial wellbeing alongside cancer treatment is, thus, a paramount consideration.

Notable group that experiences the lack of psychosocial support in their cancer journey are adolescent and young adults (AYAs), youth between ages 12-18, AYA patients feel isolated during their oncology treatment journey (Avutu et al., 2019) The needs of this patient group warrant particular attention. Important factors are accessibility of social support to favour all patients', particularly AYAs', social development and patient recovery as well as mitigate isolation.

Literature suggests psychosocial support programs (e.g. peer support groups) are effective interventions to help paediatric oncology patients manage long-term complications of cancer, increase their resilience to challenges and minimize stress (Deegan et al. 2023; Nilsson, Segerstad, and Olsson 2022; Weidman et al. 2021). However, accessing support is notoriously difficult due to lack on trained professionals and intergenerational knowledge. This deficit is compounded by long wait times, stigma and lack of recognition for the role of psychosocial support in overall wellbeing. The global zeitgeist of the fragmentation of healthcare systems and current global affairs has also exposed issues of access to healthcare services.

Where families must pay for healthcare services, socio-economic status can create significant disparities in health outcome. The basic principles of global health, the right to health for all, are impeded upon in this arrangement. In response, several countries have established national or provincial universal healthcare plans intended to provide a nation-wide high standard of care. While UHC's are beneficial, their degree of utility relies on two assumptions. The first is the assumption is that all services required by patients are delivered free of charge through the UHC. The second is that the major source of a particular inequitable health outcome is socio-economic, and the UHC is making a particular service equally accessible to all citizens.

This project sought to understand the degree of access that pediatric oncology patients living in nations with UHC have to psychosocial support. It seeks to identify classes of barriers (e.g. social, legislative, political) within a nation and understanding their origins, as well as the impacts of those barriers. As the barriers identified may not be specific to psychosocial support, cancer patients, pediatric patients or any combination of these three dimensions, this project also hopes to comment on lags in access to other healthcare services.

2.0 Methods

This project was divided into three phases with different purposes and methodologies.

2.1 Phase One

Phase One consisted of accessing videos and documentaries on paediatric cancer through YouTube and other public video-sharing platforms. Two books, the Emperor of All Maladies by Siddhartha Mukherjee and Fatal to Fearless by Kathy Giusti, were also read. The purpose was to provide perspective on the psychosocial challenges faced by patients and their caregivers as well as understand patients' cancer journey from their perspectives.

2.2 Phase Two

Created by Jean-Frederic Levesque and colleagues in 2013, the Levesque Conceptual Framework for Healthcare Access is a method of gaining multi-dimensional perspective into patients' access to specific healthcare services. Access in the Levesque Framework is assessed through the perspective of healthcare systems and patients within their context. Use of the framework in research is intended to provide a holistic yet patient-centered understanding how various factors aide or impede access at stages of care seeking. The Levesque Framework visually arranges these factors, which may be minor bulwarks or result in complete loss of access to psychosocial support, into dimensions.

Through extensive literature reviews, Levesque and his team identified the most common factors and characterized them into five major dimensions impacting healthcare system-driven use of services: Approachability, Acceptability, Availability and Accommodation, Affordability, and Appropriateness. The five dimensions are then assessed in the perspective of the patient as ability to 1) perceive; 2) seek; 3) reach; 4) pay; and 5) engage. Use of the dimensions of accessibility and ability set the Levesque Framework apart and makes it a powerful tool. By allowing researchers to separately assess the same five classes of barriers from two sources, the health systems' shortcomings in providing care (accessibility) and people's abilities to access said care (ability) can be distinguished (Cu et al., 2021).

This project implements the Levesque Framework *a posteriori* by extracting information from existing resources and assigning them to one of the five Levesque dimensions. The Framework is also commonly used *a priori*, with the Levesque dimensions guiding the curation of participant questionnaires or interview questions. While other projects may use the Levesque Framework to classify gaps in healthcare access, this project uses the framework to identify strengths and gaps under each Levesque dimension. This will enable comparison across different data points.

The data collection sheet used in this project was created based on the Levesque Framework with the following modifications based on the Phase One literature review:

1. Addition of an "Appointment Engagement Mechanism" sub-dimension under "Availability and Accommodation"

Purpose: To investigate if changes to the delivery of psychosocial support were made to cater to youths' individual needs

2. Addition of a "Compensation" sub-dimension under "Affordability"
   Purpose: Investigate if reimbursements are a barrier to access

Scientific literature, hospital websites, reputable news sources and policy/legislative documents were used to collect data. These sources were chosen as they provided unbiased data and represented nation-specific perspectives on access to psychosocial care. Each source was categorized by the Levesque factor and dimension it fell under based on the information it provided. After data collection, the strengths and gaps illustrated from each nations' literature review were consolidated to identify the most common and systemic sources of access gaps. The consolidation was done for individual nations and repeated combining information from all nations assessed.

This project intended to represent countries from different continents and socio-economic stratas, though all nations shared either national or regional-level UHC plans. Six countries – Canada, South Africa, Luxembourg, Mexico, Russia and Pakistan – were selected to be investigated.

Canada, representing the high-income bracket and North Americas, was chosen out of both personal interest as a Canadian citizen as well as to assess the success of provincial/territorial allocation of funds from a federal budget. Canada functions with decentralized single-payer public healthcare, with the Canadian government establishing national standards (the Canada Health Act) for its provinces and territories. Once approved by the federal government, budgets for each province and territory are paid to the provinces and territories through the Canada Health Transfer. The healthcare plan covers all Canadian residents.

South Africa, representing the upper-middle income bracket and Africa, was chosen because of its incumbent Prime Minister's plan to establish a national UHC program. A two-tier system, providing public and private sector care, used to run in South Africa. 80% of the population relied on the publicly funded care, though inadequate funding and management impairs proper delivery. The remaining 20% of the population would rely on private healthcare, which is delivered by groups who unaffiliated with any government. The new UHC system called the National Health Insurance scheme, implemented starting May 2024, will remove private funded care to "deinstitutionalize healthcare". It further restricts citizens from accessing private healthcare insurance for services provided by the new National Health Insurance Scheme; this restriction is "globally unprecedented" and is a controversial change (Chothia, 2024).

Luxembourg, representing the high-income bracket and Europe, was chosen as it spends the largest proportion of its federal healthcare budget on mental health in the world. It also spends the most money per resident globally. Overseen by the Luxembourg National Health Fund, the national public healthcare system guarantees universal health insurance, the ability of patients to choose their providers as well as fixed fees and services that providers must comply with.

Mexico, representing the upper-middle income bracket and Latin America, was selected because it allots the largest amount of its health budget out of all other Latin American countries

to mental health. In recent years, Mexico has been increasingly transitioning away from a public healthcare system. Employed citizens and citizens who can afford to voluntarily enrol are covering through the Instituto Mexicano de Seguro Social scheme. Non-qualifying citizens were previously covered through the Seguro Popular system, which covered remaining citizens with fees charged proportional to household income. The Seguro Popular system was eliminated in 2020 and the incumbent administration promised to strengthen the public system by increasing the quality of care (Kaule et al., 2023). Even prior to the elimination of Seguro Popular, there were high wait times for specialist procedures.

Russia, representing the upper-middle income bracket and Europe, was selected as it had the third highest DALY rate for childhood cancer patients. The country has a centralized healthcare system and designates delivery to state jurisdiction. Obligatory Medical Insurance is a public fund that covers all employed Russian citizens, though public contributions are around 2% of the GDP less than the Organisation for Economic Co-operation and Development (OECD) average contribution.

Pakistan, representing the lower-middle income bracket and Asia, was selected because it had the third highest death rate of children to childhood cancer as of the same 2019 study (CITE). Aside from the publicly funded healthcare for employed citizens, the Sehat Sahulat Program (SSP) was created in 2015 and is working to provide free healthcare coverage for marginalized populations. Horizonal healthcare delivery mediums have been particularly successful at reaching Pakistan's rural population, particularly in delivering care to marginalized populations. However, underfunding for public healthcare, inadequate training of already few healthcare professionals and limit the public and SSP schemes (Muhammad et al., 2023).

Figure 1: Nations included in this study, mapped. The nations chosen for study strive to be socio-economically and geographically diverse.

3.0 Results

Phase One involved qualitative analysis of two novels. Both pieces highlighted cancers' impact on patient wellbeing.

3.1 Siddhartha Mukherjee's biography of cancer, The Emperor of All Maladies

In this work, Mukherjee details the stigma of cancer patients faced in the hospital setting. Early in cancers' history without knowledge of or screening for cancer, children would die suddenly and without explanation. Early cancer research describes the disease etiology as a "black bile", a metaphor for its elusiveness. Even after an illness like cancer was hypothesized, research was slow due to a lack of funding.

Hospitals are described as dark, dreary places; antiseptic gleams of the hospital floor, patients donning hospital smocks like prisoners' outfits. The adult cancer patients in the book testify that their lives were changed from their diagnosis, feeling isolated, guilty and misunderstood. While the book doesn't capture the emotions of pediatric oncology patients, it details the specific fears and stigmas surrounding pediatric oncology. Children in pediatric oncology wards were seen for their cancer diagnoses and its symptoms. The absence of discussion around psychosocial support for paediatric oncology patients highlights a system lack of recognition for its importance. Mukherjee also exposed a knowledge gap in pediatric oncology due to lack of research funding from the US federal government. This gap in funding was and continues to be filled by public and private philanthropy. Currently in the United States (US), only 4% of the 5.6 billion dollars spent by the national government for cancer research funds paediatric cancers. Philanthropy continues to be a significant funding source in the US and globally.

3.2 Kathy Giusti's Fatal to Fearless

Giusti focused on empowering American cancer patients to advocate for themselves in a fragmented medical care system that have limited resources available. Giusti wrote about her battles with cancer as a working mother of three. The author also highlights the hopelessness she had to confront and how she ultimately beat cancer with the support of her immediate family and loved ones. While very valuable, Giusti's work was beyond the scope of this project. It focused on fighting cancer physiologically and expediting the treatment process, not on accessing forms of psychosocial support. This suggests that patients themselves don't recognize the need for psychosocial support during cancer treatment and in survivorship. Giusti's also spoke to how her unique position in the healthcare system due to her career in business and healthcare empowered her to keep seeking support, a "resource" that many families lack.

Phase Two involved a systematic review of online resources.

3.3 Dimension One: Approachability and the Ability to Perceive

Table 1: Sub-Dimensions of Dimension One and Countries with room for improvement

Approachability		**Ability to Perceive**	
Transparency	South Africa, Russia, Pakistan	**Health beliefs**	South Africa, Mexico, Pakistan
Outreach	Canada, South Africa, Mexico, Luxembourg, Russia, Pakistan		
Information	All		
Screening	All		

Approachability

3.3.1 Transparency

Increasing awareness about the need for psychosocial support means sharing credible information with patients using public-friendly language. In Luxembourg, national news sites are a repository for information sheets and resources on citizens' psychosocial wellbeing. For example, Rao (2024) and Silva (2024) are webpages that are regularly updated with mental health resources for citizens. The European Society for Pediatric Oncology (SIOPE) provides publicly-available factsheets so citizens can learn about SIOPE countries' oncology initiatives (SIOP Europe Secretariat, 2024). A lack of data collection or systems/groups to publicly report research findings may hinder this factor. One option is pediatric oncology patient registries (Mallon et al., 2021).

3.3.3 Outreach

Outreach to bridge children, parents and healthcare professionals to share the importance of mental health in a patients' treatment and survivorship journey are vital. For example, Canadian Partnership Against Cancer (2021) explains a method for physicians to refer their patients to psychosocial support. However, use of this resource by patients is dependent on a physicians' awareness of the resource existing. Public outreach to physicians and patients by groups who create support resources is, thus, required if patients are to make full use of their resource.

3.3.4 Information

Information about population health is published in technical and non-technical sources. Consistent use of terminology is particularly important if families should understand the published information. For example, chronic illness isn't consistently acknowledged as a source of mental distress. Terms that refer to psychosocial support like "intensive care" are poorly defined and vary

in how they are used. A term like “intensive care” associated with psycho-oncological support for a young patient can magnify stigma (Leiva, 2020).

Seemingly “untechnical” terms, terms used outside a scientific setting and oncology, may also be misinterpreted or misunderstood by families. For example, “adverse event” can be interpreted to include a comorbidity like declines in patient psychosocial wellbeing. For example, The National Cancer Institute writes, “[s]pecific treatments for childhood cancer, especially those that directly impact nervous system structures, may result in sensory, motor, and neurocognitive deficits that may have adverse effects on functional status, educational attainment, and future vocational opportunities.” However, “adverse events” refers to symptoms or unintended signs in patients temporally associated with their use of a medicinal product (ICH, 1994). Delineating between or defining terms, miscommunications can arise.

3.3.5 Screening

Physicians would benefit from diagnostic methods to assess young patients’ psychosocial needs made specifically for young patients. A lack of pediatric-specific diagnostic tools is common in childrens’ health; diagnostic tools and other methods to hear from young children haven’t been developed. For example, a deficit in Patient Reported Outcome Measures (PROMs) available for patients under age eight arose from the assumption that young patients couldn’t accurately report how they felt. Research now shows that patients as young as three can accurately report their physical pain, so healthcare providers/researchers are now creating PROMs for younger patients to fill the gap (Decruynaere et al., 2011). Screening tools for psychosocial support like the Supportive Care Needs Survey are only for patients aged 18. Screening methods to identify children who would benefit from psychosocial support should be age appropriate to be accurate. For example, Mahakwe et al. (2021) mention that pictorial methods of assessing anxiety are best for young children to understand the subject matter of the assessment, but pictorial screening tools don’t exist.

Because of the belief that children can be represented through their parents, we lack diagnostic tools for pediatric psychiatry. Parents’ reports to physicians may initiate support options. However, Tembe et al. (2021) reported that parents’ perception of their children’s psychosocial wellbeing is higher than children’s reports. Instead of parents’ reports, physicians should hear directly from children. A method to do so is through self-portraits. 78 children aged 7-12 receiving treatment for Stage One cancer at the Children Cancer Hospital, Karachi, Pakistan were asked to draw self-portraits. The common emotions in their portraits were sadness, seriousness, anger and pain. Pictures especially focusing on hair loss and missing body parts, uniformly reflecting low self-esteem. Most drawings reflected childrens’ isolation, emotional detachment from or abandonment by family members.

Ability to perceive

3.3.6 Health literacy

Inadequate literacy in pediatric healthcare systems contribute to the lack of awareness of pediatric patients' psychosocial needs and reduces available opportunities for establishing psychosocial support infrastructure. Farooq et al. (2023) reported that "[d]ue to a lack of funding and administrative interest, pediatric oncology units in LMICs do not actively invest in psychosocial services, often not recognizing its impact on children and their families." Many countries also lacked country-specific research on the needs of pediatric oncology patients. Data on cancer (eg. survival, quality of treatment) is routinely collected and analyzed in high-income nations and is not collected in low- and middle-income nations (Castro-Ríos & Martínez-Valverde, 2022). This knowledge gap needs to be addressed. Further, as pointed to by Galindo-Vázquez & Costas-Muñiz (2019), cultural and demographic factors impact how health services are accessed and received by patients. To ensure the unique needs of each pediatric patient and their family is met, country-specific research should identify the cultural or demographic adaptations needed to best support patients.

3.3.7 Health beliefs

Physical health is prioritized over psychosocial wellbeing for pediatric oncology patients. Only recently have health systems started to focus on patient wellbeing rather than the absence of physical ailment. However, psychosocial needs are critical when patients are "recovering" and/or trying to return to normal life. With survival rates of pediatric oncology patients improving, more young cancer patients are entering survivorship and can achieve a higher quality of life with continued psychosocial care.

Particularly in low- and middle-income countries, the "psychosocial domain of evidence based care assessments lacks attention compared to the physical domain." (Lemmen et al., 2023). Parents predict that their childs' physical function is the most important outcome for their healthcare-related quality of life, contributing to neglection of their psychosocial wellbeing. It is also believed that psychosocial support is for patients who have recovered from cancer. Families accordingly report that support services drop significantly after cancer care (Michel & Vetsch, 2015). However, per Marusak (2024), there are three phases at which childhood cancer impacts patient mental health: during diagnosis, treatment, and survivorship. Survivorship is particularly important for pediatric patients, as it can be accompanied with long-term struggles adapting to a life after intensive treatment and isolation. Psychosocial support is vital at all three stages of a patients' cancer journey.

3.4 Dimension Two: Acceptability and Ability to Seek

Table 2: Sub-Dimensions of Dimension Two and Countries with room for improvement

Acceptability		Ability to Seek	
Professional Values	All	Personal and Social Values	All
Norms	South Africa, Mexico, Russia, Pakistan		
Culture	South Africa, Mexico, Pakistan		
Gender	South Africa		

Acceptability

3.4.1 Professional values, Norms, Culture and Gender

There is a systemic deficit of acknowledgement of pediatric oncology patients' psychosocial needs by health systems, healthcare professionals and communities. Even multinational health promotion groups like the Pan American Health Organization (PAHO) don't include psychosocial support in their guidelines for how to support paediatric oncology patients (eg. the PAHO's CureAll Framework). Organizations like PAHO should reinforce these priorities, particularly because they are supported by research findings.

Resources from the WHO and PAHO report higher than average mortality rates for Russian and Mexican paediatric oncology patients (WHO, 2021) (PAHO, n.d). Like the "life over limb" approach, nations with poorer survival rates for pediatric oncology patients may choose to focus on reducing mortality before improving quality of life for surviving patients. This battle of competing interests - addressing patient mortality and supporting patient quality of life through psychosocial support - can be balanced through offering in-hospital psychosocial services to paediatric patients. Multi-disciplinary or integrated care teams consisting of physicians, oncologists, can also be formed for patients at a care site.

A lack of formalized indicators for healthcare professionals to assess their patients' psychosocial wellbeing is a deterrent to professionals adopting screening into their practise ((=Jones et al., 2018) (European Reference Network, 2024). Formal systems and indicators endorse the need to support patients psychosocially, and their absence leaves providers without guidance. Patients would also benefit from a multinational standard of care to ensure that regardless of location, all patients receive quality psychosocial care.

A standard of care would be most effective if it was customizable. Tailoring psychosocial treatment plans to patients' personal needs rather than using generic approaches for every patient – who each have individual needs - can enhance treatment outcomes and survivorship (Friedman & Mulhern, 1992). For example, paediatric patients who've undergone chemotherapy have shown neurobehavioral morbidity affecting various areas of their cognitive functioning (eg. memory,

academic achievement, emotional health) (Ikonomidou, 2018). Patients who've undergone reconstructions or cosmetic surgeries struggle with their functionality, social acceptance and self-esteem, particularly school-aged patients. These groups of patients have different psychosocial needs from each other. Sleiffer (2022) reports that these benefits of psychosocial support can be tailored to patients' cancer types and demographic factors.

Similarly, multinational standards for pediatric psychosocial support driven by research on a single country are not endorsed. For example, a CANSA factsheet uses research from nations like the United States, very geographically and culturally distinct from South Africa, to illustrate the need for psychosocial support. Such sources overlook context-specific factors (CANSA, 2023). For example, females in South Africa will commonly avoid seeking healthcare because of gender-based stigma (Arlene Swinny et al., 2021). Vital context-specific factors like these can be missed by using a certain countries' characterization of issues as the basis for solutions in others. Multinational diagnostic standards, though, must be flexible. The ICD-10, created by the World Health Organization (WHO), is an international classification standard used by healthcare professionals to diagnose and characterize illnesses focused on diagnosis, research, reimbursement, statistical tracking, and mortality data. The standard guidelines don't include patients with "sub-threshold and clinically significant psychosocial/existential syndromes" who concurrently have a chronic condition like cancer (WHO, n.d). Patients in this sub-threshold, clinically significant category would benefit from psychosocial support and should be accounted for in data collection and screening. Developing a specific tool to screen for subclinical syndromes may be useful to prevent exacerbation of psychosocial conditions.

Ability to Seek

3.4.2 Personal and Social Values

Stigma continues to be an impediment in access to mental health support. As stated by Braillon (2019), "[m]isconceptions and social stigmas towards patients with mental health problems prevent social attendance and help-seeking behaviour." Scherer & Bolton Oetzel (2003) from Pakistan notesthat the stigma many adolescents associate with psychotherapy to be a barrier to them seeking treatment. Stigma around cancer in certain cultures further discourages patients from accessing care.

Similarly, stigma around mental health prevents parents from sharing information their childrens' psychosocial needs with others. The Mental Health Commission of Canada found that 40% of parents say they will not tell anyone - including family physicians - if their child is "experiencing a mental health problem" (Mental Health Commission of Canada, 2023). This means that both children and their parents are discouraged from talking about psychosocial needs due to stigma, making it unlikely that this need will be shared with healthcare providers. It is worth noting that a paper from Pakistan found parents perceive their childrens' overall health-related quality of life of cancer patients similar to their childrens' reflection of their quality of life (Chaudhry & Siddiqui, 2012). However, Tembe et al. (2021) from South Africa found that patients themselves often report lower psychosocial functioning compared to their parents.

From Pakistan, Qadir et al. (2023) notes that "timely proper diagnosis, good healthy behavior of health care professionals and nurses and positive psychological therapy may be useful to reduce the stress level, effectiveness of social stigma, anxiety and hopelessness in pediatric leukemia survivor children."

A study of healthcare professionals from Mexico reported that only 25% of invited healthcare professionals attended an anti-stigma training for mental health, highlighting a lack of recognition of mental health's importance or stigma amongst professionals (Lagunes-Cordoba et al., 2022). While this study concluded their voluntary psychiatric training program increased awareness for psychiatric health services, the study used only a post-training survey to assess participants' appreciation for psychiatry. Because professionals voluntarily participated in the training, healthcare professionals who opted into the training likely had requisite appreciation for or interest in psychiatry. Thus, professionals would be likely to report an appreciation for psychiatry after the experimental training regardless of whether they participated in it or not.

In decentralized healthcare systems (eg. Canada), a lack of federal funding and mismanagement of state/provincial funds impede healthcare delivery (Jacques & Perrot, 2024). Centralized systems with state-specific implementation (eg. Russia) have improved accountability. A publicly underfunded healthcare system is a risk in all nations.

3.5 Dimension Three: Availability and Accommodation, and Ability to Reach

Table 3: Sub-Dimensions of Dimension Three and Countries with room for improvement

Availability and Accommodation		Ability to Reach	
Geographic location	All	Social supports	All

Availability and Accommodation

3.5.1 Geographic location

Since psychosocial support is often delivered in-person in hospitals and community centers located in predominantly urban areas, families in rural areas need to travel into urban centres to access needed care. For example, there are no paediatric oncology treatment sites in the three Northern territories of Canada (Canada's Children's Hospitals Foundations, n.d.). Patients in these settings must travel to different provinces to receive treatment. Luxembourg has only one oncology treatment site for childhood patients, and available information suggested that this site is a paediatric hematology clinic (Heindrichs, 2022) (Centre Hospitalier de Luxembourg, n.d.)Patients are routinely referred cross-border to neighbouring Brussels or France because no specialists exist for their diagnosis. There are no cancer survivorship clinics in Luxembourg ((SIOP Europe Secretariat, 2024).

Urban-rural disparities could be improved by offering virtual psychosocial support sessions and networks, dependent on internet capacity. Granted sites are accessible and while initially counterintuitive, integrated health teams at paediatric oncology treatment centers could additionally benefit as patients would be able to receive both oncological and psychosocial

interventions during visits. A study from Mexico found integration of care teams from different areas of wellbeing would also aid physicians' awareness of the importance of psycho-oncology (PAHO, 2021).

Ability to Reach

3.5.2 Social supports

Philanthropy, non-governmental organizations and community primary care organizations facilitate access to psycho-social wellbeing when government policy or social movements cannot. Since Sidney Farber's Jimmy Fund for paediatric cancer research in 1948 starring young Einar Gustafson, many fundraising campaigns have used the ethos of childhood cancer to fund research. In Luxembourg, donations to the countries' only pediatric cancer center foundation allow every family needing to travel to and stay in neighbouring countries for treatment to do so for free. This scale and volume of coverage is difficult to replicate in other settings due to Luxembourg's' small patient population, but the initiative is a good one. While donations predominantly fund cancer research (paediatric cancers are systematically under-researched and are poorly understood), hospital networks are used to fund psychosocial support programs. For example, some groups use their youth mental health center to demonstrate their commitment to patients' wellbeing. Drawing attention to psycho-oncology can improve recognition of the issue amongst the public and can increase financial support from the public.

Community primary care organizations and non-governmental organizations can provide care when it is unable to be delivered by primary care sites like hospitals. Community primary care organizations serve to connect local patients with local trained professionals. This specificity is intended to provide patients with healthcare, community services and programs specifically tailored to their local communities' needs. It is also intended to relieve pressure from hospitals, provide care to marginalized communities who feel discouraged from visiting hospitals and keep patients from having to leave their communities. Particularly due to the stigma attached to mental health, many needs for personalized psychosocial care can be absolved through reliance on community primary care organizations. It is worth noting that community-based interventions interfere with the benefits of multi-disciplinary/integrated care teams. The benefits of a geographical network of professionals outside of primary care sites and those of integrated care sites need to be balanced.

When supplied with trained professionals and resources, NGO's can function like community based primary care centers. For example, there is high risk of losing patients to follow-up when they enter adult or survivorship care. NGO's, similar to community organizations, can address this patient group and provide transitionary support (Olarte-Sierra et al., 2021). However, the Life Esidimeni Tragedy from South Africa's Gauteng Province demonstrated the need to strengthen NGOs before referring patients to sites. In efforts to "deinstitutionalize healthcare", the Gauteng Province Department of Health closed a major psychiatric hospital and transferred all patients to NGOs. Lack of prior health documentation, coordinated transfer of patients and notice to patients' families made the transfer logistically challenging. Some of the NGOs patients were transferred to were unlicensed, which ultimately resulted in the deaths of 144 patients.

3.6 Dimension Five: Appropriateness and the Ability to Engage

Table 4: Sub-Dimensions of Dimension Five and Countries with room for improvement

Appropriateness		Ability to Engage	
Adequacy	All	Caregiver Support	All
Technical and interpersonal qualities	All		
Coordination and Continuity	All		

Appropriateness

3.6.1 Adequacy

For a support to be adequate, it must be age appropriate. While pediatric patients are overlooked in oncology care, adolescents and young adults (AYAs; patients aged 12 to 18) are particularly isolated because of their unique developmental position (eg. independence, identity, sexuality) (Avutu et al., 2022). This means these older patients have unique psychosocial needs that are overlooked in pediatric care facilities (Weiflog et al., 2015). Out of all six countries studied, only two countries – Canada and Luxembourg – had programs to specifically support AYA oncology patients (Norsa, 2016). Run by the Canadian Partnership Against Cancer and the European Society For Medical Oncology (ESMO) AYA Working Group respectively, the initiatives deliver online and asynchronous learning modules.

It has been accepted that psychosocial support must be delivered differently to patients of different ages. AYA patients traditionally show low engagement in psychosocial support activities, though personalized psychosocial support plans and hybrid support groups are ways that care sites have begun reaching more AYA patients (Reed et al., 2014). Sources recommend that multidisciplinary integrated care teams, establish essential requirements for AYA treatment centers, promote autonomy and facilitate social interaction are optimal interventions (P. Thornton et al., 2020) (Ferrari et al., 2021).

3.6.2 Technical and interpersonal qualities

There is a lack of trained professionals in paediatric psycho-oncology, paediatric psychiatry and more broadly, in psychiatry. South Africa reported one of their major gaps in child psychiatry was lack of trained professionals (O Mokgaola et al., 2022). Factors contributing to this gap include stigma around mental health, lack of available formal training and the acceptability of the career. In Pakistan, a study by Larsen et al. (2022) reported this lack of training resulted in lack of engagement of teenage cancer patients in face-to-face talk psychotherapy. Lack of economic compensation for healthcare workers similarly results in a lack of trained professionals in Canada.

3.6.3 Coordination and continuity

International organizations serve to motivate countries to support paediatric oncology patients. In the countries researched, the WHO, PAHO and the European Union (EU) were the most present. For example, the WHO's global CureAll framework commits nations to focusing on diagnosis, interventions through UHC plans, treatment protocols, monitoring, advocacy, and finances and policy. These frameworks and their accompanying indicators help to standardize assessments of progress across countries. While the CureAll framework doesn't explicitly mention psychosocial support for patients, such tools are nonetheless useful. PAHO and the WHO monitor nations' progress using the CureAll framework indicators, and produce public data and reports.

Similarly, the EU has created frameworks to monitor nations' progress. The European Society for Paediatric Oncology (SIOPE), collects data from research organizations and provides guidelines, analyzes data from patients and families. The SIOPE is a division of the International Society for Paediatric Oncology (SIOP). This creates national and international level synergy.

A major project by the SIOPE is the Survivorship Passport, a consolidation of information relevant to patients' diagnosis as well as patient and cancer type-specific health indicators to be reviewed by providers during follow-ups. Progress on this initiative has lagged due to the laborious process of crafting the passports, though these patient-specific schemes are starting to be widely implemented after the SIOPE's research identified them to be the "best solutions" (Albrehet et al., n.d.). The interconnectedness of the SIOPE with groups like the European Society of Paediatric Oncology (ESMO) for health data ensures the effectiveness of interventions. The EU also has developed a standard of practises for each type of cancer,) though can be better implemented in psycho-oncology when read with the WHO's guidelines for mental health and wellbeing (European Reference Network, 2024) (ICD, n.d.).

In short, national standards of care and trends can be supported through national and international level bodies though they should not supplement community level primary care psycho-oncology strategies. A study by Jenkins (n.d.) from Mexico found that nation-wide guidelines were useful to establish standards of care, with regional implementation strategies being the most effective. Thus, national standards derived from international health groups like the WHO and PAHO and the EU and the SIOPE must instead inform the implementation of regional-level strategies.

Ability to Engage

3.7.4 Caregiver support

Caregivers play a significant role in survivors' wellbeing, particularly parents. Knowledge gaps amongst parents are thus crucial to address. Per the findings of Tembe et al., (2021) , parents' understanding of wellbeing as purely physical impede their ability to support young patients. Per Maryam et al., (2022) "[e]very parent has different understanding which are influenced by multiple factors such as language barrier and literacy level. It was found that proper evaluation of needs and delivering requisite information is crucial for the effective process and outcome." In particular, in Pakistan and other Asian countries family dynamics are more conducive to providing psychosocial support avenues through family rather than through other professionals. This arises

as a potential avenue to circumnavigate parental stigma. However, sources like Maryam et al., 2022 concurrently mention that parents should receive psychosocial support rather than provide psychosocial support to their children. Friedman (2024) found that parents of children with cancer access psychosocial care more than other parents and supported the need for routine follow-up appointments for caregivers.

Greatest weak points in paediatric cancer patients' ability to access psycho-oncology are the following:

	Approachability	Acceptability	Availability, Accommodation	Affordability	Appropriateness
Canada		X			
South Africa		X	X		
Luxembourg			X		
Mexico		X			
Russia			X		
Pakistan			X		

4.0 Discussion

These research findings indicate that UHC plans are not enough to provide psychosocial care for pediatric oncology patients. The modified Levesque Framework analysis demonstrates that even when affordability is controlled for, acceptability, availability and accommodation of psychosocial support hinders its delivery to patients. Stigma, lack of endorsement and geographical disparities were the largest and most consistent contributors to these barriers. While these research findings can't be directly extrapolated to illustrate a global trend, addressing these three issues may significantly improve accessibility to support worldwide.

A factor that may influence interpretation of these research findings is patient population. Luxembourg has a remarkably small population, with only 6 paediatric oncology patients dying of cancer per year. This figure can be compared to the 10 000 children dying of cancer in Latin America yearly; while the region contains 33 countries, Mexico makes up 19.4% of the population of Latin America and has a paediatric oncology diagnosis rate of 156.9 patients per million citizens per year. The fewer number of patients a country sees, the lower the socio-economic and resource load on their healthcare system, and the less adequately nations can provide paediatric psycho-oncology care. This could explain why nations like Luxembourg perform well in delivering care. However, Luxembourg's attentiveness to psychosocial support illustrates that attention to the need for support is not alone gained by having a large patient load.

There is also armed conflict in Russia as this research was being carried out, so collected data may not reflect current healthcare delivery. There may be increased need to psychosocially support patients, as the added stress of armed conflict presents challenges to padiatric patients' wellbeing (Uğurluer et al., 2022).

5.0 Recommendations

From data collection, the following recommendations arise:

1. Implement integrated care centers at all paediatric oncology sites.
2. Strengthen community primary care sites to provide psycho-oncology support for survivorship and follow-up care, and specific resources to support marginalized groups in with in-person and virtual modes of delivery.
3. Continue involvement in international health promotion bodies.
4. Continue involvement in continent/region-specific divisions of health promotion bodies.
5. Create organizations integrated under continent/region-specific division of health promotion bodies with:
    a. A focus on paediatric oncology.
    b. Indicators to assess progress made in psycho-oncology.
    c. Capacity to analyze health data and disseminate research-driven recommendations.
    d. Capacity to periodically update and communicate research with the continent/region-specific division, as well as the general public.

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