Laidlaw Scholars Undergraduate Leadership and Research Programme

Research Proposal

A scoping review of forms of psychosocial support are available to pediatric oncology patients in nations with universal healthcare

Neha Gupta

Dr. Sandy Lee

April 15th, 2024

STUDENT LIFE | Centre for International Experience

UNIVERSITY OF TORONTO

Abstract

In our time and space, attention to holistic views of health and healthcare delivery are top of mind. The delivery of healthcare is now understood to implicate psychosocial support. However, access to psychosocial support is not broadly implemented particularly for subsets of patients like pediatric oncology patients. Cost, social stigma and social factors – unavoidable by socio-economic incentives like universal healthcare plans – impede access to psychosocial support, with more barriers given the complex circumstances of pediatric cancer patients. This project seeks to name, categorize and understand potential barriers making it difficult for patients to access psychosocial support. To answer this research question, this project will employ a qualitative methods approach by accessing publicly available resources to understand how patients in communities around the world access psychosocial support. Ten countries will be investigated and compared using the Levesque Conceptual Framework of Access to Healthcare, a five-component framework based on common barriers faced by patients in accessing care. Sources will include hospital resources, legislation, policy and others. Comparisons between nations will be drawn and similar trends in access gaps will be identified. The findings from this project can potentially inform policy and practices on how to effectively integrate psychosocial supports into patient care and more broadly, make access to this and other forms of psychosocial care more accessible.

Introduction

The world is coming to recognize that health consists of more than the mere “absence of illness”, but requires a holistic assessment of spiritual, psychosocial, physical and mental wellbeing. In healthcare settings, this has led to recent interest in items like Patient Reported Outcome Measures, various qualitative assessments of patient health and addressing mental health as a source of patient wellbeing aside from physiological illness.

Pediatric cancer care particularly emphasizes the need for social support and interactions to support a child's development and recovery. Literature underscores the effectiveness of psychosocial support like peer groups for young cancer patients. However, accessing such care is often hindered by long waits, stigma, and financial strain, even in countries with universal healthcare, revealing disparities in health service accessibility. This project seeks to understand to what degree paediatric oncology patients living in nations with universal healthcare plans can access psychosocial support. More importantly, this project seeks to identify the most potent barriers to accessing this care and understand their basis (eg. are they prominently social, socio-economic, geographical etc.).

Medical treatment must extend beyond biological factors to include psychosocial wellbeing. The current urgency for support has been accentuated by COVID-19, social media influence, insufficient awareness of need and lack of expertise and more. Childhood cancer and mental health support are global issues that necessitate interdisciplinary collaboration for holistic wellbeing. Together, they create a specialized niche worth investigating.

Research Objectives & Questions

Research Question: What, if any, forms of psychosocial support are available to pediatric oncology patients in nations with universal healthcare? Are there barriers to accessing this support?

Primary Objective

- Assess the degree of accessibility of psychosocial support for pediatric patients

Secondary Objectives

- Understand if there are age-related, racial, cultural, socio-economic, geographic or other socially driven barriers to accessing psychosocial support
- Identify if trends in accessing psychosocial support for pediatric patients is mirrored in other patient demographics
- Understand if being a patient connected to or being treated at a healthcare network/institution facilitates access to psychosocial support
- Understand if universal healthcare plans cover psychosocial support

Background

Cancer is a complex illness and is further complicated in pediatric patients due to their physiological development, long term bodily and social detriment, involvement of children in decision-making and more (Hasan et al, 2021). As such, unique aspects of childhood cancer like separation from other children their age, barriers to schooling and effects of treatment on their developing bodies are considered by healthcare systems in treating these young patients (Federico, Brennan, and Dyer 2011). Of particular importance is the need for social support and interactions to favor a child's development and aid patient recovery. Addressing a child's social wellbeing alongside cancer treatment is, thus, a humanizing and paramount consideration.

Literature suggests psychosocial supports like peer groups are an effective way of supporting pediatric oncology patients in helping manage long-term complications of cancer, increasing resilience to challenges and playing a protective role against stress (Deegan et al. 2023; Nilsson, Segerstad, and Olsson 2022; Weidman et al. 2021). However, accessing such support is notoriously difficult. This deficit is compounded by long wait times, stigma and the down recognition of the role of psychosocial support in overall wellbeing. The global zeitgeist of the fragmentation of healthcare systems and current global affairs has also exposed many to issues of access to healthcare services. Integrated healthcare systems, systems with facilities like biomedical and psychosocial services available under one roof, arise as useful solutions (Dawda, 2019).

Accessing care, psychosocial support included, is a source of significant financial stress. For citizens living in nations with universal healthcare, a prevailing assumption is that all services required by patients are delivered free of charge. However, in a job at SickKids Hospital, I noted that this was not the case for many families who were precariously dependent on which political party held the majority at the time. Further, costs covered under universal

healthcare plans are indicative of the formulary and treatments that a locality or government feels is necessary to the wellbeing of their stakeholders. It is thus useful to assess the accessibility of psychosocial support through universal healthcare.

Methodology

The methods in this project are all qualitative. All research will be completed in the research period (elaborated on in Timeline). This project will be conducted independent of organizations/labs, and it will rely on publicly available data. This project no travel to accomplish its objectives.

The scholar will seek out many types of sources to understand how a pediatric cancer patient can access psychosocial support in the context of their health network, universal healthcare plan coverage and broader community. This will be guided either by Google Searches (eg. searching for lists of psychosocial support locations in a region) or targeted reading of selected websites (eg. reading through national-level health legislation/acts). Sources accessed may include hospital procedures, government websites, policy and scholarly literature reviews.

The scholar currently plans on applying the Levesque Conceptual Framework of Access to Healthcare, which has only recently begun being applied to psychosocial support. The framework uses five main dimensions – Approachability, Acceptability, Availability and Accommodation, Affordability and Appropriateness – which were devised after a review of literature by Levesque and colleagues in 2013 (Cu et al. 2013). This framework provides a method of assessing social, socio-economic, availability and sector-driven barriers that contribute to healthcare accessibility. It also provides a structured and domain-centered way of standardizing analysis of access to support provided the diversity of sources and nations being scoped.

The scholar will meet virtually with the project research supervisor, Dr. Sandy Lee, weekly as Dr. Lee is based outside of Toronto.

The scholar aims to abide by the conduct ethical research guided from learning outcomes from TCPS 2: CORE-2022 (Course on Research Ethics) training received last summer through the Panel in Research Ethics.

Training/ Certifications Needed

No training or certifications are required for the completion of this research project.

Research Location

The scholar will remain in Canada for the full duration of the research period.

Research Ethics Board

This project does not require Research Ethics Board approval.

Timeline

Phase One: Preparatory period (May 30th to June 9th)

- Conduct a literature review through PubMed, Google Scholar on the psychological needs of children with chronic illness.
- Read two books:
    - Fatal to Fearless: 12 Steps to Beating Cancer in a Broken Medical System by Kathy Giusti
    - The Emperor of All Maladies by Siddhartha Mukherjee
- Complete Ontario Health's Pediatric Oncology Course
- Shortlist five to ten nations to conduct research on based on factors like most recent universal healthcare debates, political climate and childhood cancer prevalence.
    - Nations will aim to be representative of all continents to represent the global burden of childhood cancer and produce universally applicable recommendations

Phase Two: Solidify and pilot the analysis procedure (June 9th to June 16th)

- Identify factors of interest to collect when conducting country-specific research (eg. hospital-based psychosocial support programs)
- Choose which five types of online platforms I will use to collect data from (eg. hospital websites, government budgets, legislative assembly websites).
- Create a data collection sheet on Microsoft Excel with appropriate column headings, conditional formatting etc.
    - Down the X Axis, ten country names will be listed. Each different source accessed for that particular country will be listed in the cells beneath the country name.
    - Down the Y Axis, rows like "Source Type", each of the five Leveque Factors, "Additional Comments" etc. will be used.

Phase Three: Data collection (June 17th to July 18th)

- Between two and four days will be spent on focused research for each nation of interest
    - Using the Google Programmable Search Engine, internet searches for specific countries will be performed by programming my browser to retrieve search results from the nation of interest. This would mimic how cancer patients and their families would search for resources in their respective countries.
    - Using a language translating service (PRO version of Deep L for Chrome), documents and webpages in foreign languages will be translated to English to minimize construing findings. The software will be purchased and installed onto my device prior to/on June 17th.
    - Two countries per week will be completed for two weeks (June 17-23 and June 24-30). The following two weeks, three countries will be completed a week (July 1-7 and July 8-15).
- July 16th to 18th will be dedicated to
    - Clean up data sheet.

    - Use consistent words and phrases to describe findings from all source types.
    - Complete citations for all the sources accessed in the data collection process

Phase Four: Summarizing findings (July 19th to July 29th)

- Complete a Results write-up based on Phase Three
    - Summarize important quantitative and qualitative findings
    - Identify important trends across data
    - Ensure all data fits into the Levesque Framework
- Create a skeleton outline of a journal article or research paper deliverable

Resources & Support Needed

This project requires a personal device with internet connection. Any supports needed will be in guiding methodology or specific areas of research, which the scholar will defer to the research supervisor for input.

Potential Impact

This research will generate both qualitative and quantitative data that reflects the ability of pediatric oncology patients able to access psychosocial supports in various nations. Other outcomes include assessing the priority the psychosocial support is given in pediatric oncology care and how universal healthcare plans may alleviate the burden of accessing supports.

The field of psychosocial support for pediatric patients, let alone subsets of pediatric patients, is small. This research project will summarize current steps taken by nations around the world towards supporting such patients. Thus, this report can bring much-needed attention to this under-researched global issue. It can expose systematic gaps in how nations integrate psychosocial support for patients receiving hospital care, and can also provide valuable insight on universal healthcare plans' ability to support mental health visits. This study is also uniquely transnational, meaning the findings of this project implicate the transnational patient, family and healthcare provider population.

Budget

Provided separately.

References

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