MACH
Melbourne Academic
Centre for Health

MacHSR Future Leaders Fellowship program
Final reporting (Cohort 2)

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Project title: Stakeholder perspectives and developing consensus in integrating patient-reported outcome measures into routine clinical care for paediatric liver transplant patients.

Report

Overview of the original problem and approach

In Australia, the current 10-year survival rate after paediatric liver transplant (PLT) is 95%.[1]
Despite excellent long-term survival, PLT patients have a lower quality of life (QOL) across all domains compared to healthy peers.[2-4] QOL encompasses the domains of physiological including functional status and energy levels, social factors including social health and social support, psychological factors including emotional status, self-esteem, body image and cognitive variables, and normal child development in paediatrics.[2,5] For PLT recipients, these challenges can persist throughout childhood and into adult life, limiting the ability to lead a meaningful and socially inclusive life.[6] Liver transplantation offers a life-long treatment, rather than a cure, with life-limiting diseases replaced by a need for life-long medications, and monitoring of graft functioning, both transplant- and medication-related complications and for some, disease reoccurrence.[7] For children, the neurocognitive effects of pre-transplant hepatic encephalopathy or brain injury from metabolic instability[8] and potentially long-term immunosuppression therapy may impair physical, emotional and intellectual development[7]. Further, the psychological toll of the journey from primary disease to transplant through to long-term survivorship on patients and caregivers can have lasting impacts on well-being and adjusting to life after transplant.[7]

Patient-reported outcome measures (PROMs) collect subjective data about a patient's symptoms, functional status and quality of life.[9] Integrating PROMs into routine care enables clinicians to monitor well-being and identify problems enabling earlier tailored interventions. At an individual patient level, this can facilitate superior communication between patients and families with healthcare providers, patient-centred care and direct resource allocation.[9,10] At a service and organisational level, aggregate data can provide evidence of treatment effectiveness and identify areas within health services that may require systematic changes for quality improvement. These result in improving outcomes that are meaningful to patients enabling them to thrive, aligning with The Royal Children's Hospital Melbourne's (RCH) vision. Further, patient-reported outcomes using validated tools facilitate contemporaneous evidence- based objective data capture to inform organisational performance indicators, towards supporting RCH strategic priorities, such as *promoting the importance of the health and wellbeing of every child and young perso*n.

Notwithstanding international recommendations from transplant experts,[4] neither systematic measurement of patient-reported outcomes nor integration of PROMs into routine care within liver transplant services has been established in Australia. Additionally, despite PLT-validated PROMs being available, no consensus exists on tool selection within the international PLT community, nor on health outcomes to measure after PLT.

As a leading paediatric hospital, there exists a professional obligation of the RCH to measure patient-reported outcomes and strive to provide data-informed care for diseases and treatments that have a proven detrimental effect on quality-of-life. The Nationally Funded paediatric liver transplant service at RCH aims to integrate PROMs within clinical care for all PLT patients to capture patient-level data and to support patient-centred care, resource allocation and improve long-term patient outcomes. This innovative practice change aligns with the strategic goals of the RCH, providing data to assess and address well-being and support thriving.

The health service problem we are trying to solve is how best to approach and facilitate the transition from the decision to use PROMs to systematic and sustainable integration in routine clinical care in PLT at RCH. Experts

in implementing PROMs in organisations identify that this requires behaviour change and structured implementation guided by implementation science theories and frameworks.[11,12] A key element in informing the critical foundation of implementation is exploring stakeholder perspectives in capturing health outcomes not currently captured by conventional assessments allowing identification of barriers and facilitators to implementation within an organisation.[11] The International Society for Quality of Life Research recommends selecting PROMs to use for a specific patient cohort through stakeholder consensus.[13]

The aims of this project in developing and building a co-designed evidence-based approach to implementing PROMs in routine clinical care for PLT patient were:

- To explore stakeholder perspectives, including patients, caregivers and healthcare providers on integrating PROMs into routine clinical care;
- To develop consensus with paediatric liver transplant experts across Australia and New Zealand in patient-reported health outcomes for measurement and tools to capture health outcomes, and;
- To develop a PROMs community of practice and PROMs working group within the organisation to identify best practices in approaching implementation within RCH and establish data governance.

Refinements to the project

Initially, the project aimed to explore stakeholder perspectives in implementing PROMs in paediatric liver and heart transplant services at RCH. However, in early discussions with my RCH and MACH supervisors, we decided to focus only on the liver transplant service, given the allocated time available within the scholarship and that I had previously researched health outcomes after liver transplant and relevant PROMs, and therefore, had a strong framework to develop the research in liver transplant. Research outcomes and insights from our own experience could be shared with peers in cardiac transplant to support future work.

In addition, we had considered asking patients, caregivers and clinicians to select appropriate tools to capture patient-reported health outcomes that were seen as important to capture. However, we identified that this would be too onerous for patients and caregivers on top of exploring their perspectives on using and implementing PROMs, especially if they were unfamiliar with PROMs. Therefore, our project was refined to include a modified e-Delphi survey with liver transplant clinicians throughout Australia and New Zealand to develop consensus in patient-reported health outcomes for measurement and the tools to capture these.

Activities, achievements and impacts

1. **Study protocol**
    a. A mixed methods study protocol was prepared and submitted to ethics.
        i. Peer review identified the initial proposal for the modified e-Delphi protocol as unfeasible due to the number of rounds and input being requested from the participants and the need for funding for the remuneration of participants
        ii. Refinements to the protocol based on this review are pending finalisation
        iii. Funding for simple remuneration (i.e. car park passes at a minimum) for participants still being sought
    b. Familiarisation resources and study documents for participants were developed, and caregiver and patient resources were piloted by PLT recipient caregivers
        i. Refinements made based on suggestions, awaiting stakeholder review
2. **Co-led the development of a 'PROMs' community of practice and working group within RCH**
    a. Successful executive endorsement of PROMs working group within the RCH Clinical Excellence Committee, aligning with the ACSQHC National Care Standard: Comprehensive Care
3. **Introduction to Health Services Research (single subject) at the University of Melbourne - completed**
4. **Abstract accepted and presented (poster) at conferences** (previously completed literature review and semi-structured interviews with subject matter experts to understand unique patient-reported outcomes in PLT survivors and develop recommendations for integrating PTMS into routine clinical care):
    a. Transplantation Society of Australia and New Zealand Annual Conference (Melbourne)
    b. International Society for Quality of Life Annual Conference (Germany)
    c. RCH Annual Nursing Research and Clinical Innovations Symposium (Melbourne)

5. **Presented on using PROMs in paediatric care:**
    a. Murdoch Children's Research Institute Data Week
    b. RCH PLT team
6. **Visited KLIK (abbreviation for 'Quality of Life in Clinical Practice') research team at Emma Children's Hospital in Amsterdam (2 days)**
    a. The KLIK research team shared their experience and expertise in the systematic and sustainable implementation of PROMs since 2011 within an online platform that has a front-end integration into electronic medical records
    b. Met with a paediatric nephrologist with expertise in capturing QOL data in children with kidney transplants since 2012, and attended outpatient appointments to observe the use of KLIK within routine care
7. **Transplant Nurses Association and RCH scholarships** to attend the International Society for Quality of Life conference in Germany, and visit the KLIK team in Amsterdam
8. **Networking with Australian and international researchers with interest and expertise in PROMs**

Barriers or delays you faced:

- Completing the Introduction to Health Services Research Unit within the first half of the one-year program was essential in helping me finalise my methodology, however, it meant that I had half a year to work on the project after completing the unit
- An MCRI honorary appointment was required for me to access the REDcap database to use for data capture for my project, with resulting time delays.
- Protected time wasn't always guaranteed when other team members were on leave or secondary to a high clinical workload
- There were challenges in coordinating meeting times and arranging protocol reviews within preferred timeframes with busy project (RCH) and MACH supervisors
- Essential refinements to the study methodology, protocol and patient/ caregiver-facing study collateral added to delays in finalising the protocol (anticipated)
- Within RCH, there is no data governance related to PROMs and no standard approach to data capture, storage and presenting PROM data within the existing EMR within RCH. These are identified as critical to successful PROMs implementation, and therefore, were a focus of the PROMs working group and are needed to be established before future implementation activities
- PROMs working group – delays in establishing executive endorsement due to organisational restructuring
- Funding for simple remuneration (i.e. car park passes) for study participants still being sought

Plans for continued activity

- I have made plans to continue the project within my own time and am planning to include other clinicians within the RCH PLT service within the research team to support the project.
- I am continuing as a member of the RCH PROMs working group

Resulting collaboration and industry engagement

- Invitations to and active collaboration with MCRI and RCH researchers on PROMs research projects
- Significant interest within RCH across other specialties, and from other paediatric and adult transplant units throughout Australia in the project outcomes
- Invitation to present at a Transplant Nurses Association education event on PROMs
- Writing a research paper for The Transplant Journal of Australasia (previously completed research which informed this project)
- Interest from the Transplantation Society of Australia and New Zealand Patient Outcomes Working Group for me to share my expertise in PROMs in establishing the working groups' strategic plan
- Interstate and international networking with paediatric organisations implementing PROMs in routine care
- Interest from Victorian Paediatric Clinical Network in Statewide approach to using PROMs in routine paediatric care

Summary
The fellowship has been a wonderful opportunity for me to strengthen my skills in health services research, and to network and build collaborative working relationships within and external to RCH. I am more confident in my research skills, and I have been able to better support others in their research. The fellowship has enabled me to innovate and feed my curiosity to find the best way to solve difficult problems. I have been able to share these skills and experiences with other clinicians within RCH to support their work and research endeavours. I am also continuously strengthening my skills and knowledge in PROMs implementation, which I am thrilled to share with colleagues to support the use of PROMs in clinical care.

References

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