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ORIGINAL RESEARCH

Fifteen years of shared care for paediatric oncology, haematology and palliative patients across Queensland: The role of Regional Case Managers

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Abstract

Objective: A shared care model was implemented in 2006 in Queensland to facilitate paediatric oncology, haematology and palliative care patients receiving care as close to home as possible. Following initial diagnosis, care planning and treatment at the tertiary children's hospital, appropriate local care was coordinated by Regional Case Managers (RCMs) established at each of 10 Shared Care Units (SCUs). This enabled safe and quality regional care supported by a statewide network providing clinical governance and education. This paper examines learnings from 15 years of this shared care.

Setting: Ten hospitals throughout Queensland facilitated a statewide model of shared care for paediatric oncology, haematology and palliative care patients, supported by a tertiary hub in Brisbane.

Participants: Regional Case Managers in Shared Care Units and their supporting staff.

Design: Staff from SCUs were surveyed and focus group interviews conducted.

Results: The paper reviews the attributes, knowledge and experience required for RCMs. Standards of care were supported through education workshops, clinical placements, chemotherapy credentialing, guidelines and standards. RCMs facilitated communication and information sharing with the tertiary centre, advocated for their cohort of patients locally and streamlined and supported the family's experience of care.

Conclusion: The RCM role provided invaluable clinical leadership for the care of paediatric oncology, haematology and palliative patients across Queensland. As new treatments evolve, the expertise and coordination provided by the RCMs will be even more critical. Achieving high-quality shared care outcomes is

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underpinned by the RCMs drive to achieve statewide safety and support for this cohort of children.

KEYWORDS
care coordination, family centred care

1 | INTRODUCTION

Cancer in children and adolescents is rare, with 0.5% diagnosed in 0–18-year age group in high-income countries.[1] With collaborative research across the globe, the 5-year paediatric cancer survival rate has risen to 85% in 2015.[2] Optimising survival requires complex treatment by highly specialised inter-professional paediatric oncology, haematology and palliative care teams that are typically embedded in tertiary hospitals. In Queensland, Australia, sustaining this is challenging when geographical boundaries are extensive. Providing skilled care as close to home as possible is the desired outcome.[3,4]

Queensland's population of 5.1 million (2019) spans over 1.7 million square kilometres, seven times the size of the United Kingdom where the population is over 66 million.[5,6] More than half of Queensland's population resides outside of the Brisbane metropolitan area where the State's only tertiary children's hospital is located. In Queensland, there are approximately 250 new diagnoses of children with cancer or haematological conditions each year, and around one-third are referred from regional and remote areas as defined by the Australian Statistical Geography Standard (ASGS).[7]

A major challenge of a statewide service is to ensure equity of access and quality of care to regional and remote patients, or at any hospital away from the tertiary centre. From a family perspective, access to local facilities, reduced travel and cost and the emotional support available to a child/young person and carer within their local community provide a compelling case for localised services.

Establishing equity and quality of care in the context of complex life-threatening illness across large geographical distances challenges the establishment of any treatment model. Although hospitals throughout Queensland have a busy general paediatric caseload, some centres have limited exposure to complex paediatric conditions and their treatments, thus limiting the skill base and experience of staff.[8,9] To address these challenges, the Queensland Paediatric Palliative care, Haematology and Oncology Network (QPPHON)[10] was established in 2006 to provide governance and support of a shared care model. QPPHON is based in the tertiary children's hospital in Brisbane and it informs decision-making at service delivery and corporate levels, through expert advice relating to the development and maintenance of service provision across Queensland and northern New South Wales (Brisbane being their closest tertiary centre).

What this paper adds:

- This paper shares the learnings from 15 years of shared care of children with cancer and haematological disorders, and those requiring palliative care, throughout the large and diverse state of Queensland, applicable to any specialist service provided at a distance from the tertiary centre
- The learnings are drawn from the perspectives of those providing shared care in hospitals close to the patient and family's home after diagnosis, care planning and some treatment are performed at the tertiary centre. Shared care away from the tertiary centre may include low-risk chemotherapy and supportive care
- Practical guidance is provided for specialised nursing in Shared Care Units regarding role requirements, education and professional development, information sharing, the clinical environment, the shared care unit team, family support and coordination of care

What is already known on this subject:

- Health and wellbeing outcomes for paediatric patients and their families are improved by receiving care as close to home as possible
- Shared care with a tertiary centre facilitates safe and quality specialised care in rural areas
- A rural role that coordinates shared care, advocates on their patient's behalf and provides education and support for staff and families is a valuable asset

The leadership of QPPHON provides stewardship to the network of shared care with a strong advocacy role and commitment to the delivery of safe care, including oversight of quality initiatives, research, education, coordination, and project management and implementation. This is provided through a Paediatric Oncologist (QPPHON Chair), a Nurse Manager (co-chair), a Statewide Educator, an Allied Health Clinical Leader and a Program Manager. Governance is provided by the Director of the Oncology Services Group of the tertiary children's hospital.

The QPPHON shared care model enables the tertiary centre to facilitate the provision of safe and appropriate care within Shared Care Units (SCUs).[11,12] Following initial diagnosis and treatment, children can return home and receive treatment determined by the specialist at the tertiary centre.[12] SCUs manage inpatient admissions for these children, provide supportive care, administer low-risk chemotherapy in outpatient/day-care settings and blood product transfusions when required. The referring General Practitioner and/or Paediatrician continues to be informed about the patient's status. The service levels provided across the 16 statutory Hospital and Health Services (HHSs) are determined through the overarching Queensland Health Clinical Services Capability Framework that minimises risks associated with delivery of specialised treatment.[13] This type of shared care model has been in place in several countries with different geographical and population stratifications.[14,15]

Sharing care for children and young people between a specialist centre and health providers closer to home has been demonstrated around the world to be a useful model for the management and treatment of conditions such as cystic fibrosis,[16] ADHD,[17] obesity,[18] cardiac transplantation,[19] general paediatric care[20,21] and children with complex needs.[22] Shared care had the same[16,19] or improved outcomes including patient comfort levels, and decreased emergency and day-only admissions.[17,18,21,22] Care was more accessible, sustainable and supportive,[18] there were reduced costs to the family and health system[21,22] and better quality of life for the children.[22] Factors reported to improve shared care included web-based software to share information and monitor progress,[18] clear roles,[20] 24-hour hotline for support[21] and strong linkages to general practitioners.[21]

With the establishment of QPPHON in 2006/2007, dedicated Regional Case Manager (RCM) positions were funded in 10 SCUs in hospitals away from the tertiary centre in Brisbane. These were at Cairns, Townsville, Mackay, Rockhampton, Bundaberg, Hervey Bay, Sunshine Coast, Toowoomba, Logan and Gold Coast. These specialist nurse positions were created to provide care coordination and treatment under the leadership of a nominated lead paediatrician and in collaboration with the tertiary centre. They also collaborated with smaller hospitals in the surrounding health jurisdictions (HHSs) if they were able to provide supportive care closer to the patient's home.

The main goals of the RCM role included:

- Delivery of safe and high-quality services in their nominated area.
- Delivery, evaluation and coordination of patient care at an advanced level
- Planning, delivery and evaluation of education programs

QPPHON facilitated the development of service agreements between the HHSs and the tertiary centre. To improve safety and quality, QPPHON collaboratively provides and updates statewide clinical guidelines, standardised procedures, information resources and education. Informal and formal communication is regular and collegiate. RCMs provide activity and safety round reports to QPPHON. SCUs are reviewed regularly by QPPHON leaders during on-site visits to determine compliance with standard guidelines and procedures to ensure safety in clinical practice.

The aim of this study was to examine how the role of the RCM in SCUs adds value to the outcomes for paediatric oncology, haematology and palliative care patients and families, the changes and development of the role over time and the benefits provided to patients and families.

2 | RESEARCH METHODS

Regional Case Managers involved in the QPPHON shared care model participated in the study through an online survey and face-to-face focus groups (Table 1). The study included all RCMs in SCUs across Queensland who had been in their role for greater than 3 months or had left that position within 12 months.

The Australian Statistical Geography Standard – Remoteness Area (ASGS) uses five levels of remoteness

TABLE 1 Reponses to the survey and participation in focus groups by Shared Care Unit

Shared care unit	Responded to survey	Participated in focus group
Cairns	1	1
Townsville	1	2
Mackay	1	2
Rockhampton	2	1
Bundaberg	1	3
Hervey Bay	1	1
Sunshine Coast	1	2
Toowoomba	1	1
Logan	1	1
Gold Coast	2	4
Total	12	18

based on a measure of relative access to services. Three of the SCUs were located in areas classified as Major City (Sunshine Coast, Logan and Gold Coast), Cairns and Townsville were in outer regional areas and the other SCUs were located in inner regional areas.

2.1 | Survey

The survey (Appendix A) used and expanded upon a validated survey used in a study of cancer nurse coordinators in Western Australia.[23] The online survey was distributed to RCMs in July 2018 with 12 responses, including all of the 10 current RCMs and 2 past incumbents. Completion of the survey was accepted as consent as all the RCMs were co-investigators in the study and were cognisant of its scope, risks, benefits and governance. The survey covered the RCM nursing experience, establishing the role, workload, referral processes and initial contact with patients and families, along with daily tasks and challenges in the role, achievements, outcomes and future service planning. Survey results were analysed using Microsoft Excel to determine averages and frequency of responses.

2.2 | Focus groups

The focus group interview questions were based on the research question, to determine the scope, evolution and benefits of the Regional Case Manager role (Appendix A). They explored the value and outcomes of the RCM position, its contribution to family and local staff support, changes experienced in the role over the years and its sustainability.[15] Two focus groups were conducted during an annual RCM's workshop in May 2018, using semi-structured interviews and led by the QPPHON Nurse Manager and Program Manager.

The two focus groups consisted of:

1. Five RCMs (Mackay, Bundaberg, Toowoomba, Cairns and Logan) and three Clinical or Registered Nurses supporting RCMs (Bundaberg, Gold Coast and Sunshine Coast)
2. Five RCMs (Hervey Bay, Rockhampton, Townsville, Gold Coast and Sunshine Coast) and three Clinical or Registered Nurses supporting RCMs (Mackay, Bundaberg and Gold Coast)

Detailed notes were taken and consented recordings were transcribed. Separate feedback was provided by an outgoing RCM for Townsville via interview and a Nurse Practitioner from Gold Coast provided written feedback to the same questions. In total, 11 RCMs and 7 additional SCU nurses who cared for QPPHON patients participated in the focus groups. Transcripts were analysed using an inductive thematic approach, generating codes and searching for themes from the responses in collaboration with the focus group attendees.[24] All current RCMs in 2021 reviewed and commented on the results of this study.

An activity template, developed with the RCMs, was populated and provided to the QPPHON leadership on a monthly basis. The activity of each centre varied according to the number of patients in that locality, including those on long-term follow-up.

A waiver of ethics review was granted for this project by the Children's Health Queensland Hospital and Health Service Human Research Ethics Committee as a quality assurance activity on the role of RCMs, conducted within all best practice ethical guidelines and complying with the relevant sections of the National Statement on Ethical Conduct in Human Research.

3 | RESULTS

The following brings together the themes and data from the focus groups with the results from the survey.

3.1 | The RCM role

Regional Case Managers reported that passion, flexibility, patience, persistence, leadership and good communication were important attributes of their role. They needed to share information and deliver education to key staff. The recency of practice and clinical competence was vital, as well as continued development and upskilling, including learning from families and acting in other roles. They had to understand the statewide network to ensure strong collaboration and have key contacts in the tertiary centre, other local hospitals and community services.

Specialised knowledge and experience were vital for all RCM roles. Ten of the 12 survey respondents had been Registered Nurses for 10 years or more and two for more than 5 years. Half of the RCMs surveyed had been in the role for more than 3 years (two for more than 10 years) and eight had completed postgraduate studies. Although the initial funding had allowed RCMs to be appointed at a Clinical Nurse Consultant (Nurse Grade 7) level, two of the HHSs had downgraded the position to Clinical Nurse (Nurse Grade 6), while the Gold Coast had created a Nurse Practitioner (NP) position, adding value through the extended scope of practice, nursing leadership and NP outpatient clinics.[25,26]

Table 2 shows the order of priority that RCMs approached work-related tasks and Table 3 shows the importance of the various achievements of the role. Some RCMs had a portion of their time allocated to direct clinical work, while half had other roles in the hospital which could result in ambiguity in their daily tasks. RCMs suggested more support from administration staff for scheduling of appointments and more nurse hours to allow them to focus more on planning, education and support of staff, proactive support of families and widening their advocacy for children across the HHS. There were seven RCMs who routinely received nursing assistance during clinic days; others asked for support as it was required. Succession planning was supported by rotating clinical and registered nurses through the service and the RCM position for backfill.

The RCMs reported working between 0.2 and 1 full-time equivalent in their role. These hours were originally agreed based on population and historic patient data. RCMs reported an increase in referrals and complexity of patients being treated at SCUs as some children were coming home earlier in the oncology treatment protocol (Table 4). Monthly activity data collected by the RCMs (Table 5) could be used in business cases to demonstrate increases in workload; five of the RCM's had been successful in increasing their work hours from the original allocation. Some hospitals hosting SCUs had been upgraded to include paediatric critical care units and emergency departments and increased paediatric beds, which influenced their patient caseload and the need for increased RCM support.

When commencing in the role, the RCMs benefited from a handover from the previous incumbent, clinical placements at the tertiary centre and completing the paediatric chemotherapy course. As well as the scheduled education workshops, QPPHON orientated new RCMs through phone calls, emails, videoconference mentoring and buddying with another RCM. This supported the RCMs to implement appropriate paediatric procedures and pathways within their adult-focused hospitals.

> Feeling the water, seeing how things worked, what policies were established, what policies weren't....

The annual QPPHON-funded RCM workshop at the tertiary centre provided valuable networking opportunities and built up a robust, competent and supportive RCM network.

As some SCUs expanded their services, they have provided more complex treatments for oncology patients. The aim was to devolve care to the SCUs so that families could have as much treatment as close to home as possible. Careful risk assessments were undertaken to maintain the balance between safety and the benefits of care close to home.

3.2 | Advocacy

The RCMs advocated for the small but complex cohort of paediatric patients within hospitals predominantly focused on adult care, addressing the specific health care rights of children, the principles of family-centred care and specialised service provision. The RCMs advocated for additional nursing and allied health positions to enhance service delivery for children and ensured children were considered at an HHS governance level when developing guidelines. Some SCUs added paediatric staff representation to hospital committees such as a Blood Transfusion Committee and End of Life Care Committee. Strong relationships with staff in general paediatrics, adult and paediatric emergency departments and intensive care units were particularly important. A clear understanding of the

TABLE 2 Highest work priorities reported by Regional Case Managers

Workload priority	Task
1	Clinical care of a patient provided the greatest demand including chemotherapy, haemophiliac or palliative care – also non-palliative
2	Maintaining communication – telehealth, phone call, email, checking integrated electronic medical records (i.e. MR)
3	Leadership – an ongoing expectation that as an advanced practice nurses they would be involved as a role model and a paediatric representative within an adult environment
4	Education – to families and staff across the hospital
5	Support for patients post-treatment – to ensure they do not fall through the cracks – remain connected
6	Administration – patient documentation, activity reporting and risk management
7	Professional development

TABLE 3 The Regional Case Managers' perspective of the level of importance of achievements in their role

Achievement	Extremely important	Moderately important
Family trust in SCU team care of their child	12	0
There is a clear pathway for patient care	11	1
Strong collaboration and communication with teams	11	1
More children receive treatment locally	10	2
Ongoing professional development	9	3

TABLE 4 Newly diagnosed oncology and haematology patients over 5 years in Shared Care Units

Shared care unit	Population HHS catchment	2015	2016	2017	2018	2019
Cairns	247 300	9	5	11	11	16
Mackay	182 000	9	3	12	17	14
Townsville	241 300	8	8	5	10	8
Rockhampton	227 100	4	2	8	11	20
Hervey bay	212 000	2	5	0	3	2
Bundaberg		7	2	3	5	6
Sunshine coast	384 100	9	17	19	27	22
Toowoomba	276 500	4	5	3	5	5
Logan	300 000	6[a]	6[a]		3[a]	6[a]
Gold coast	560 000	12	14	21	25	20
TOTAL	2 630 300	70	67	82	117	119

[a] 6 months data only.

TABLE 5 Regional Case Manager activity in 10 Shared Care Units – Range of monthly activity by unit in the 2018–2019 financial year

Activity	Range of monthly activity by unit
Children on active treatment and up to 12 months off treatment	1–26
Review oncology children more than 12 months off treatment	0–40
Haematology patients on treatment	0–13
Patients receiving palliative care	0–7
Chemotherapy doses given	0–10
Blood products provided	0–8
Blood tests	0–16
Accessing central venous lines	0–12
Meetings, phone calls, and emails with families (h)	1–30
Outreach clinic patients seen by tertiary centre oncologist	No clinic – 47 patients twice a year
Communication with tertiary centre (h)	1–12
Education of families (h)	0–24
Education of local staff (h)	0–22

Clinical Services Capability Framework (CSCF) empowered the RCMs to advocate for the local staff to consult with the tertiary centre to discuss management of children and adolescents presenting with a possible cancer or haematology diagnosis and for shared decision-making in their care. The families saw the RCM as a safe consistent person who advocated for them and acted as a liaison with the tertiary centre.

> I am a big advocate for what is best for the kids and will fight to the bitter end to get what we need.

3.3 | Education

Nurses working in the RCMs positions required sound clinical assessment skills, experience delivering complex nursing care and a thorough understanding of procedures and protocols. The RCMs' expertise was further developed through clinical experience, continual education and support through the QPPHON Education Program. At the annual RCM workshop at the tertiary centre, they maintained chemotherapy competencies, received education updates and exchanged information with other RCMs. A collegial support network was developed and they regularly contacted each other for guidance and support. Informal monthly videoconferences between the RCMs and the QPPHON team provided a forum to discuss any issues arising, complex cases, journal articles and feedback received from families.

> I … feel we have fantastic professional and collegial support from our QPPHON colleagues.

> … being very new to the role – I didn't have any handover but … you are one call away and email … it is so much support and education and telehealth. It's just nice and you don't feel alone I think.

RCMs and SCU staff participated in clinical placements at the tertiary centre and attended in-person and videoconference workshops. This enabled them to better guide and support the families through their experience.

> I think just seeing how it all works here… I can chat to my families and say 'oh yeah I know the room that you go into and have your obs done and … that's where you go through to this room' and I think that's made a real difference with families knowing that I know what goes on.

QPPHON conducted workshops on site at the SCU every 2 years, which could be attended by any hospital staff in that area. Professional development through conferences and workshops was funded upon an application process, including the Annual Scientific Meeting of the Australian and New Zealand Children's Haematology/Oncology Group and the Advanced Palliative Care Workshop at the tertiary centre.

Regional Case Managers educated and supported the multidisciplinary team in their SCU and nearby hospitals within and surrounding their HHS, especially when there was a known local patient. The latter involved telephone communication and education of staff and ensuring the family had a copy of the febrile neutropenic pathway and a port pack. They ensured an adequate number of nurses were skilled in accessing central venous access devices and accredited to administer chemotherapy. As the majority of RCMs worked part time, they upskilled other nurses to ensure clinical work could be completed in their absence. Through ongoing education within the emergency department, paediatric ward and intensive care unit, the RCM increased staff knowledge and confidence in delivering care to these complex paediatric patients. Education topics included procedural advice, chemotherapy protocols, the management of emergencies, managing central venous access devices and blood products, and supportive care management of mucositis, febrile neutropenia and haemophilia bleeds.

> You have to stand strong in who you are and your skills and if you face something that you've not done before; you have to do your research … we all want to be backing up ourselves and using evidence-based practice.

3.4 | Sharing information

Over the years, there had been improvements in sharing of clinical information through electronic chemotherapy prescribing and patient information systems. The implementation of electronic medical records throughout most of the State had improved visibility of information, supporting patient care and safety and allowing RCMs to share tasks such as coordinating patient travel arrangements.

One consequence of electronic records was reduced informal contacts between the tertiary centre staff and RCMs. RCMs commented that they often shared more information on a phone call, e.g. "Mum's a bit fragile today." However, direct communication still took place if there were particular issues. Relationships between RCMs and tertiary centre staff were also built through workshops and clinical placements.

The standard processes for the prescribing of chemotherapy and its administration in SCUs were augmented by a pre-chemotherapy assessment form, which was developed by an RCM and shared across the State. This added another layer of clinical safety to chemotherapy administration away from the tertiary centre.

Videoconferences among the family, SCU team and tertiary centre before the child was discharged home assisted in building the family's trust and confidence in the SCU.

Regional Case Managers provided monthly activity reports, safety round reports and documentation of quality activities to QPPHON. In addition, some areas kept a record of family feedback, monitored key performance indicators and constructed annual business planning frameworks.

3.5 | SCU clinical environment

Two hospitals hosting SCUs had been relocated to new facilities to accommodate local population growth and this provided the physical space to grow paediatric services including the opening of a paediatric critical care unit, paediatric emergency department and increased paediatric beds. The growth of paediatric services in these hospitals had added to the workload of the RCMs as more specialised care could be provided locally.

In most SCUs, paediatric oncology patients did not have their own outpatient clinical area and used the treatment room in the paediatric unit or adult oncology unit. RCMs identified that a designated area was useful to reduce disturbance of other patients and to keep immunocompromised patients out of more public areas.

> We get a lot of parents say they love the fact that we are up the corridor, we're not in paeds … so they don't have to go into the cough and splutter infectious place.

It was reassuring for the families when SCUs had the same clinical equipment as the tertiary centre. This had been facilitated through aligned statewide ordering numbers in the electronic ordering system.

3.6 | SCU multidisciplinary team

The multidisciplinary team including medical, nursing and allied health roles varied between each SCU but may include social work, psychology, music therapy and physiotherapy. Pharmacy support for chemotherapy was vital and a dedicated oncology pharmacy/pharmacist was felt to improve safety.

Regional Case Managers valued having a paediatric team that worked well together and understood the needs of the patients. Designated lead paediatricians allowed continuity for the families as well as an avenue for escalation of clinical issues. The lead paediatricians and associated registrars received specific medical education at the annual QPPHON Paediatrician workshop at the tertiary centre. This workshop provided opportunities to discuss complex cases and receive updates on new treatments and clinical trials.

> When I first started … I had to find whoever was on call. A lead oncology paediatrician makes a huge difference because they are the go-to person.

Communication between the multidisciplinary team members was assisted by the RCMs. One SCU developed informal monthly group supervision for the team in an hour following the clinical meeting. It included constructive feedback, discussing specific problems and presenting case studies, journal articles, incidents, prevention, communication or patient death reviews.

3.7 | Family support and coordination of care

Regional Case Managers were instrumental in building the trust of families to receive care at their SCU. They facilitate a family-friendly environment and continuity of care with coordination of blood tests, chemotherapy, admissions, reviewing children on the ward and in outpatients' unit and arranging travel to the tertiary centre. The familiar face of the RCM was reassuring for families. They had ownership of the child's care and ensured all aspects of treatment were carried out in a safe and timely manner. Table 6 shows how the RCM categorised the level of importance of the various support strategies for families.

> Families are becoming more self-sufficient, due to increase in confidence, education and information.

Half of the RCMs reported that their first face-to-face contact with families was during treatment. An average of 20% had contact during initial presentation with a suspected oncology diagnosis, whereas a range of RCMs did not have face-to-face contact until after initial treatment at the tertiary centre. During treatment at the tertiary centre, the RCM could monitor progress through the shared electronic medical record system and formal and informal communication. The RCM was in regular contact with the family when they returned home from the tertiary centre for visits and encouraged families to visit the SCU to become familiar with the service and its staff. The RCMs often coordinated care at smaller hospitals within their HHS to provide local supportive care for patients.

TABLE 6 The level of importance of various activities of the Regional Case Managers' role for the family

Family support	Extremely important	Moderately important	Important	Moderately unimportant
Collaborating with palliative care teams	11			
Being readily accessible for clinical support	10	1		
Overseeing chemotherapy administration	10	1		
Being the advocate for patient care at the time of diagnosis and during treatment	9	2		
Providing ongoing education about treatment processes	9	2		
Educating the multidisciplinary staff on supportive oncology cares	9	2		
Coordinating appointments and streamlining treatment processes	9	2		
Establishing links with the multidisciplinary team	9	2		
Accessing clinical resources for a child's care	8	3		
Coordinating travel and accommodation	2	4	3	2

Note: There were no responses for "extremely unimportant".

Regional Case Managers commented on how the families appreciated the care provided at SCUs, with a consistent clinical team who knew their names and gave personalised care. SCUs held special events for the children and adopted initiatives like a bravery box (a box of toys, gift cards, games and all manner of gifts, donated by the public that can be offered to a child after undergoing a painful or confronting procedure) and chemotherapy bell (a bell rung by children who have completed treatment, often accompanied by a celebration with family and friends).

The families usually received faster treatment in a quieter SCU environment, with access to easy and cheaper parking options. Families had confidence in the link between the SCU and the tertiary centre, encouraged through the use of standardised protocols and processes. The RCM supported regular Outreach Clinics, attended by tertiary centre consultants and nurse care coordinators. RCMs also supported QPPHON consumer engagement activities including the Oncology Family Forum[27] and received valuable feedback from families.

As the treatment was generally provided over several years, families appreciated that they could have safe care close to home, with the support of their family, school and local community. This allowed the family some normality and helped with transition back to school and the social environment after treatment. The financial burden on families was reduced and it enabled improved job security. This had a flow-on effect on the quality of life for the whole family.

> I think it also reduces the financial burden on families … and it also empowers them to have engagement in their local facility and know they can go to them instead of … worry about coming down to Brisbane and they can have that point of call especially with [the RCM].

> It's also important that we help with the transition back to school. Getting kids back into that social environment with their friends and classmates… it's normalising their life.

As the RCMs had a smaller volume of patients than the tertiary centre, they could devote more time to working closely with the children and families. The RCM often had ongoing contact with families many years after treatment.

> You're in [the supermarket] and a little kid comes around the aisle and sees you … it's nice to hear that.

4 | DISCUSSION

Patients requiring specialist care at a tertiary centre, who live in regional or remote areas or at a distance from that centre, experience not just the burden of their health condition, but also the burden of being away from home. This imposes the cost of travel and decreased work-days to the patient and/or family, the possible need to change a job or place of residence, missed school days, repeated school years, changes in the management of the household and general disruption to family life.[28-30] Parents need to provide ongoing support for other members of their family, be close to their community, family and friends and maintain life as normal as possible.[31] The RCM experience was that access to shared care in hospitals closer to home reduced the burden and improved the support for families of children with cancer.

Quality shared care is supported by an RCM-type role that coordinates care and facilitates safe and high-quality service provision, advocates on their patient's behalf, streamlines their experience with services and provides education and support for staff, patients and families.[3,14,22,32] The components of the role may vary, largely shaped by the needs of the patients, families and staff in the context of the service.

In Australia, shared care is supported by care coordinators, who facilitate case conferences, monitor and update shared electronic records, increase local capability and measure outcomes.[32] Western Australia described their tertiary care coordinators as cancer nurse specialists who undertook clinical consults, nursing care, multidisciplinary care planning and education. They advocated for the families, supported their psychosocial needs and managed communication with the team.[23] Victoria followed the precedence set by Queensland, and developed memoranda of understanding with regional health services and a service capability framework, including clear guidelines on services that can be delivered safely in regional areas. Regional care was supplemented with telehealth and outreach clinics and supported through regional education.[33] In the Sydney Children's Network, shared care included shared electronic records and regular case conferencing. They also linked families through peer support networks, respite care and psychology services.[30]

The story is similar around the world. In Canada, care coordinators provided ongoing assessment, family education, communication, advocacy and support for the family with the multidisciplinary team.[3] In Norway, the care coordinator provided a link between the family and the care team, facilitating communication between health professionals and improving collaboration.[14] A systematic review of shared care emphasised the importance of communication between clinicians and families, enhancing relationships, exchanging information, managing uncertainty and making collaborative decisions.[34] Providing psychosocial support for the patient and family was a common function of the care coordinator.[23] Paediatric oncology shared care units throughout the National Health Service in the UK enable rapid access to specialised trained staff, shown in favourable time to initial presentation and diagnosis.[35]

Strong clinical leadership by the RCMs in Queensland promoted family-centred, safe clinical care and enhanced outcomes for other clinical staff and families.[36,37] Nurses play a central role in patient safety as they provide the most direct care, observe for clinical changes and initiate rescue activities.[36] The consistent support from a knowledgeable local health care specialist optimises patient/family outcomes.[36,37]

The most important goal in regional care is to ensure safety,[38] using a risk-based approach.[39] In Queensland, the delivery of care for oncology, haematology and palliative patients was in line with the Clinical Services Capability Framework, delivered by staff who have been trained and certified as competent and backed up by chemotherapy policies and procedures, facilitated by the RCMs.

Maintaining a specialised nursing practice away from the tertiary centre has risks of professional isolation, lack of back up and few peers to consult with. The RCMs relied heavily on collegial support including the local lead paediatrician, nursing leaders, the QPPHON leaders, tertiary centre care coordinators and other RCMs. Work/life boundaries for the RCMs may be challenged by high public visibility, personal relationships with patients and families and multiple roles of nurses in the community and in the HHS itself.[40,41]

The RCM had many opportunities for formal and informal meetings and collaboration, regular education and competency-based training, ongoing communication and well-being support. A previous study of the RCM roles confirmed the importance of peer support networks and ongoing professional development.[42] In addition, opportunities for specialised training were provided through QPPHON to more than the RCM as well as other staff in each SCU, to enable backup for leave and after-hours support. The RCM and one other nurse were funded to attend the annual RCM workshop in the tertiary centre, and at least three chemotherapy-competent nursing staff were required at each SCU. Regional workshops that were held on-site at each SCU attracted a wide range of staff, and included opportunities to upskill in chemotherapy, managing central venous line devices, management of febrile neutropenia and other supportive care for these patients.

In this study, the RCMs commented on the demands and frustrations that could occur in hospitals where paediatric patients were the minority. These challenges were exacerbated when caring for children and adolescents with rare and complex diseases. In these environments, the role of RCM was vitally important to ensure care was delivered safely in a timely manner and in a child- and family-friendly context.

Ongoing quality improvements recommended by RCMs included a statewide framework of responsibilities with clear role descriptions for the different levels of appointment, with expected outcomes and monitored key performance indicators, and standardised communication through mapping of information provision and templates. In addition, they called for promotion of the statewide service and their roles via a website and briefs to the HHSs, an orientation program and continued mentoring and professional development.[42]

The RCM praised the strong collaboration through QPPHON that resulted in SCUs with standard and best practice processes available for patients who resided outside of Brisbane. Families had the benefit of continuity; having a key person who understood their needs and could support them. This relationship maximised safety and provided seamless and efficient care close to home, optimising patient and family outcomes.[3] In addition, families who holidayed around the State benefited from specialised care provided by the network of SCUs. An app was developed with contact details and navigation to the SCUs and information to support the care of the patient.[43]

Regional Case Managers reported benefits for patients and families, including reduced anxiety and distress, improved understanding of disease and treatment, better coordination of appointments and supportive systems for travel and accommodation. Service-level improvements occurred through clarification of pathways, addressing service gaps and improved communication between services.[42]

By the 2011–2015 period, childhood cancer mortality across Australia was not significantly different across the regions of remoteness (major city, inner regional, outer regional and remote).[2] In addition, the differences in overall survival rates for Aboriginal and Torres Strait Islander children compared to other Australian children have decreased over time, and for blood cancers and brain tumours, survival of these two groups was quite similar in the data between 2007 and 2016.[44] The implementation of shared care across Queensland in 2006 has coincided with these positive outcomes and these results have been supported by the work of the RCMs across the State.

4.1 | Limitations

The study had some limitations related to data collection methods and timing. The consistency of data collection may have been impacted by the two focus groups that involved different staff with experience in different SCUs and the two singular responses to the focus group questions. The focus groups included supporting nursing staff, who may not have had as much extensive knowledge as the RCM themselves about the role, although had experience working with them. The RCMs interviewed and surveyed were located in 10 SCUs throughout Queensland. They had in common that they had coordinated low-risk chemotherapy and supportive care for paediatric oncology, haematology and palliative care patients outside of the tertiary centre that confirmed diagnosis and planned the treatment, but their locations had their own unique characteristics. Survey and focus group feedback was dependent on the recall of the participants.

Family feedback on shared care is not reported in this paper but was concurrently collected and a report has been written. There are no conflicting views between the two sources of information.

These data were collected prior to the COVID-19 pandemic. Although the types of treatment offered and the model of care remain the same, more opportunities were taken by families to have follow-up care in their Shared Care Unit, and specific review appointments were proactively conducted via telehealth. This has actually increased the role of the RCM in coordinating local care.

5 | CONCLUSION

This retrospective evaluation of RCMs in Queensland over the past 15 years has provided perspectives on the benefits and outcomes of the roles and how shared care has added value to the clinical care and safety of the paediatric oncology, haematology and palliative population across Queensland. The role of RCM provided statewide leadership, added safety to treatment processes and improved the families' experience of their child's treatment journey. This included advocacy, education, sharing information and working safely within the clinical environment and with the multidisciplinary team to coordinate care and provide family support.

This is an example of specialised nursing practice at its best. As new treatments evolve for children with oncology, haematology and palliative conditions, the expertise of RCMs will be constantly challenged and upgraded and their role within the SCU will become increasingly important. Achieving high-quality shared care across Queensland will continue to be underpinned by the RCMs’ drive for safety and support for this cohort of children and their families.

AUTHOR CONTRIBUTIONS

PS: conceptualisation, data curation, formal analysis, investigation, methodology, project administration, writing original draft, writing review and editing (lead) 50%; YH: conceptualisation (lead), data curation, investigation, methodology, project administration and writing original draft 28%; JN: Writing – Review & Editing 5%; MN: Writing – Review & Editing 3%; LB: Writing – Review & Editing 2%; KP: Writing – Review & Editing 2%; RP: Writing – Review & Editing 2%; AC: Writing – Review & Editing 1%; RG: Writing – Review & Editing 1%; KC: Writing – Review & Editing 1%; DP: Writing – Review & Editing 1%; CH: Writing – Review & Editing 1%; RS: Writing – Review & Editing 1%; KB: Writing – Review & Editing 1%; CC: Writing – Review & Editing 1%.

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CONFLICT OF INTEREST

No competing financial interests exist.

ETHICAL APPROVAL

A waiver of ethics review was granted for this project by the Children's Health Queensland Hospital and Health Service Human Research Ethics Committee as a quality assurance activity, conducted within all best practice ethical guidelines and complying with the relevant sections of the National Statement on Ethical Conduct of Human Research.

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APPENDIX A

Regional Case Manager survey and focus group questions

Regional Case Manager survey questions

1. What is the highest level of qualification you have obtained?

- Hospital certificate
- Undergraduate diploma
- Bachelor degree
- Postgraduate certificate
- Postgraduate diploma
- Masters or Higher
- Other (specialties) (please specify)

2. How long have you been a registered nurse?

- 1 year to <3 years
- 3 years to <5 years
- 5 years to <10 years
- 10 years or more

3. What nursing level is your regional case manager role?

- Clinical Nurse NG6
- Clinical Nurse Consultant NG7
- Clinical Nurse Practitioner NG8

4. How long have you worked in the role of Regional Case Manager?

- <1 year
- 1 year to <3 years
- 3 years to <5 years
- 5 years to <10 years
- 10 years or more

5. What is the current standard full time equivalent for your Regional Case Manager role (e.g. 0.2 FTE)

6. Has the allocation of hours changed since your commencement in the role?

- Yes (detail below)
- No

  How important has this been?

7. Do you have extra FTE for other staff to assist with your work? E.g. extra staff on clinic or chemotherapy days

- Yes
- No
- Other (please specify)

8. Do you have other roles within the hospital? E.g. adult oncology

- Yes (Please put details below)
- No

  Details of other roles:

9. On average, how many children are newly diagnosed with an oncology condition each year from your HHS (excluding haematology and palliative care)?

10. Give an estimated percentage of the stage at which you have your first face-to-face contact with oncology families?

- Initial presentation to regional hospital with suspected oncology diagnosis
- Before treatment commenced
- During treatment
- At the end of treatment
- Follow up
- At the end of life

11. During active treatment, how often, on average, are you in direct contact with the family when the patient is at home?

- Daily
- Weekly
- Monthly
- Other (please specify)

12. Are you able to monitor the treatment of the children from your region when they are at LCCH?

- Yes
- No

  If yes please explain how?

13. How important do you think the Regional Case Manager is to the family for the following areas?

	Extremely unimportant	Moderately unimportant	Important	Moderately important	Extremely important
Being the advocate for patient care at the time of diagnosis and during treatment					
Providing ongoing education about treatment processes					
Educating the multidisciplinary staff on supportive oncology cares					
Being readily accessible for clinical support					
Coordinating appointments and streamlining treatment processes					
Overseeing chemotherapy administration					
Accessing clinical resources for a child's care					
Coordinating travel and accommodation					
Collaborating with palliative care teams					

Other areas that impact on the family:

14. On your commencement in the role as RCM, how important were the following?

	Extremely unimportant	Moderately unimportant	Important	Moderately important	Extremely important
Collating known patients					
Communicating with teams, e.g. emergency, surgical, youth cancer service, allied health, tertiary institution.					
Establishing pathways					
Education of families and staff					
Developing scope of practice					
Having professional supervision (support from senior nursing staff)					

Other (please specify)

15. Did you have initial challenges understanding the oncology diseases and treatment?

- Yes
- No

If yes how did you overcome this?

16. Did you have initial challenges in achieving adequate paediatric oncology nursing skill mix?

- Yes
- No

If yes how did you overcome this?

17. Did you have initial challenges in accessing clinical treatment areas for the oncology children?

- Yes
- No

If yes how did you overcome this?

18. Did you have initial challenges in accessing appropriate clinical resources?

- Yes
- No

If yes how did you overcome this?

19. Did you have initial challenges with the paediatric/oncology team dynamics?

- Yes
- No

If yes how did you overcome this?

20. Did you have initial challenges in self-understanding of haematology/palliative care in paediatrics?

- Yes
- No

If yes how did you overcome this?

21. How important is the following to achieve in your role?

	Extremely unimportant	Moderately unimportant	Important	Moderately important	Extremely important
More children receive treatment locally					
There is a clear pathway for patient care					
Strong collaboration and communication with teams					
Ongoing professional development					
Family trust in regional team care of their child					

Other (please specify)

22. What documents show outcomes from your service?

- Achieving Key performance indicators
- Annual business planning framework
- Monthly activity reports
- Monthly safety round reports
- Documented parental feedback
- Quality activities
- Other (please specify)

23. On average, estimate how many hours/week of your role involves the following:

- Clinical care
- Education to families
- Education to staff
- Collaboration with NGOs, community nurses, tertiary institution
- Providing leadership
- Administrative work
- Other activities

24. On average, estimate how many hours/week do you spend on the following:

- Chemotherapy administration
- With haemophiliac patients
- Supporting children on active chemotherapy treatment
- Supporting children post treatment on follow up care
- Assisting a child's return to school
- Supporting a family through palliative care
- Other please explain

25. On average, estimate how many hours/week are you involved in the following:

- Patient documentation
- Telehealth, phone calls, emails
- Following up on critical incidents
- Professional development
- Reflection and documentation of outcomes
- Professional supervision
- Other – miscellaneous

26. Do you have regular multidisciplinary meetings at your site?

- Yes
- No

If yes are all the team allocated paediatric FTE?

27. Does your Hospital Health Service (HHS) recognise the advanced practice nursing role of the RCM?

28. Since you commenced in your role what changes have you seen? E.g. patient satisfaction, treatment changes, clinical outcomes.

29. What changes would you like to aim for in the future?

Focus group questions

1. What was important to consider with the establishment of the Regional Case Manager (RCM) position (or in your commencement in the position) for paediatric oncology/ haematology/ palliative care?
2. Describe how you think the role of RCM may contribute to families and staff in your organisation?
3. What do you see as important outcomes of the RCM role for patients and families?
4. What feedback have you received from families and staff about the RCM role?
5. What changes have you seen during your time as RCM?
6. Any suggestions for future development of your role?
7. With increasing demands upon time and resources, are there factors which may enhance the future sustainability of the RCM role/position?
8. Can you describe ways in which QPPHON could provide additional support to you and your service and what (if any) areas does QPPHON currently assist you?