Pediatric and child health nursing: A three-phase research priority setting study in Western Australia

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ABSTRACT

Purpose: Priority settings are important to plan and direct future research. The aim of this study was to identify the top ten pediatric and child health nursing research priorities from the perspectives of consumers, community, and healthcare professionals in Western Australia.

Design and methods: This study used an adapted James Lind Alliance Priority Setting Partnership design with three phases. 1) A planning workshop to inform a survey. 2) A survey using five open-ended-questions distributed between October 2020 and January 2021 through social media and healthcare professionals' emails. Responders' statements were analyzed with content analysis. 3) A consensus workshop to finalize and rank the themes.

Results: The planning workshop participants ($n = 25$) identified gaps such as community child healthcare and confirmed lack of consumer engagement in previous studies. The survey responses ($n = 232$) generated 911 statements analyzed into 19 themes. The consensus workshop participants ($n = 19$) merged and added themes, resulting in 16 final themes. The top three ranked themes were: 'access to service', 'mental health and psychological wellbeing', and 'communication'.

Conclusions: The research themes are necessarily broad to capture the wide range of issues raised, reflecting the scope of pediatric and child health nursing.

Practice implications: The priorities will inform future research to be directed to areas of priority for stakeholders who have often not had a say in setting the research agenda.

Background

Nurses provide care and support to children and adolescents in hospitals and community healthcare who face a variety of health conditions, diseases, and disabilities. They meet children from different cultures, developmental stages, and with individual strengths, resources, and challenges (Fowler & Stockton, 2021; Lewis et al., 2021; Mörelius & Foster, 2021). Nurses working with children aged 0–18 years focus on the child and also collaborate with and support the family with an overall aim to improve health outcomes for the child (Coyne et al., 2018). Nursing care provided needs to be informed by the best available evidence and continuous research is necessary to meet such requirements (Rossi et al., 2020). Since research is a lengthy

and costly process, it needs to be of importance to the child, their family, and nurses. To ensure that the most appropriate and important topics are researched, there is an increasing necessity to set research priorities (National Institute for Health Research, 2018). Pediatric nursing research priority studies have traditionally focused on nurses' views. In a recent review of eight priority setting studies, there was a single focus on the perspectives of nurses in identifying priorities and the important involvement of consumers and inter-disciplinary healthcare professionals were not recognized (Mörelius, Foster, & Gill, 2020).

Priority setting for pediatric and child health nursing research is important to plan, coordinate and direct future research for the nursing care of children and their families across a range of healthcare contexts. However, previous nursing research priority studies have focused on acute care, with fewer priorities reflecting areas of child-, school-, or mental-health (Brenner et al., 2014; Raman et al., 2021; Ramelet et al., 2012; Sawin et al., 2012; Tume et al., 2014; Tume et al., 2015; Tume et al., 2020; Wilson et al., 2010).

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One previous priority setting study originating from Western Australia (WA) (Wilson et al., 2010), focused on hospital care and directed the local research agenda for subsequent years (Gill et al., 2012). Since then, the Child and Adolescent Health Service (CAHS) in WA has changed. In addition to the children's hospital the service now encompasses community child and adolescent health, child and adolescent mental health, and neonatology. Identification of contemporary nursing research priorities across the new organization with the involvement of consumers including adolescents, parents/guardians, and inter-disciplinary healthcare professionals is now timely. This project will inform future research to ensure it is coordinated, relevant, and effective, and provide direction for policy makers, researchers, funders, and industry for the next years.

The James Lind Alliance (JLA) Priority Setting Partnership (PSP) is a not for profit organization established in 2004 to bring patients, carers, and healthcare professionals together in collaboration to address and agree on future research priorities (National Institute for Health Research, 2018). The JLA methodology is the most used deliberative process that facilitates an equal partnership between patients, carers, and healthcare professionals, to identify and prioritize research areas and questions on which to focus (National Institute for Health Research, 2018).

The aim of this study was to identify the top ten research priorities for pediatric and child health nursing, from the perspectives of adolescents, parents/guardians, community, and healthcare professionals in WA.

Methods

Design

This prospective study used an adapted JLA PSP process (Bower et al., 2018; Fisher et al., 2016). The process consisted of three phases 1) a planning workshop to inform a survey 2) development of and distribution of an online survey and 3) a consensus workshop to establish the top ten priority areas for future research in pediatric and child health nursing (Fig. 1). The main difference between the original and the adapted JLA PSP process is that the latter starts with a workshop instead of a survey and therefore includes just one survey (National Institute for Health Research, 2018).

Ethical considerations

Approval was received from the Health Service Human Research Ethics Committee and reciprocal approval was received from two Universities. Survey participants were provided with written participant information and were informed that consent was inferred by submission of the survey. In addition, adolescents were required to provide a digital signature from their parent/guardian, indicating consent to participate in the survey. Participants in the workshops provided informed consent. During the workshops, food and beverages were provided throughout the day. Parents/guardians and adolescent participants received reimbursement payments for their time and travel costs.

Setting

The study was conducted in WA, Australia's largest state with 33% of the total land mass and a population of 2.76 million where 1.7 million live in the state's capital Perth (Australian Bureau of Statistics, 2016). The CAHS is the state-wide service serving a population of 610,000 children and adolescents (Commissioner for Children and Young People, 2021) across areas of neonatology, community health, mental health and pediatrics. Perth Children's Hospital is WA's specialist pediatric hospital and trauma center with 298 beds, where medical care is provided to children aged 0–16 years.

The steering group

The steering group included researchers with experience from neonatology, community child health, health psychology, school nursing, and acute pediatrics. Five of the seven authors are nurses. The two workshops were led by an experienced consumer advocate and PSP facilitator and supported by the research team and an involvement coordinator. The partners in this PSP were adolescents, parents/guardians, community members and healthcare professionals.

Inclusion criteria

Participants were English speaking; adolescents over the age of 14 years with experience of receiving healthcare at CAHS; parents/guardians of children with experience of attending CAHS for healthcare; healthcare professionals working at CAHS in the last two years; and community members with an interest in the research who were not required to have experience with CAHS.

Process

Phase 1, planning workshop

Participants were recruited through the nursing research youth and consumer advisory groups and health professionals' emails. The aim of the workshop was to obtain stakeholder group input to inform the steering group on the best approach to take for the study (such as recruitment strategies, participant characteristics to collect and survey questions) and to discuss research themes identified in a previous scoping review to identify gaps and areas still requiring focus. The scoping review's four main themes were; pediatric contexts, evidence-based practice, child and family centered care, and pediatric nursing, with 14 sub-themes (Mörelius, Foster, & Gill, 2020).

Phase 2, survey

Information obtained from the phase 1 workshop informed an online survey containing participant characteristics and five specific questions to identify topics for future pediatric and child health nursing research (Table 1). Face validity was addressed through extensive
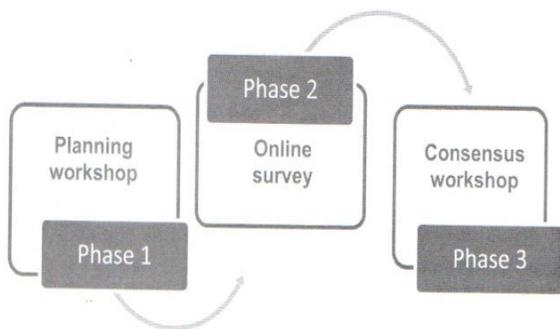

Fig. 1. Adapted James Lind Alliance Priority Setting Partnership.

Table 1
Survey questions.

|	Question
1	What is important to you to better support and/or meet the needs of children and young people?
2	What is important to you to better support and/or meet the needs of families?
3	What is important to you in meeting the needs and better supporting nurses to care for children, young people, and families?
4	What do you think future children and young people's nursing research/projects should focus on?
5	Do you have any other comments or questions about anything else to do with children and young people's nursing?
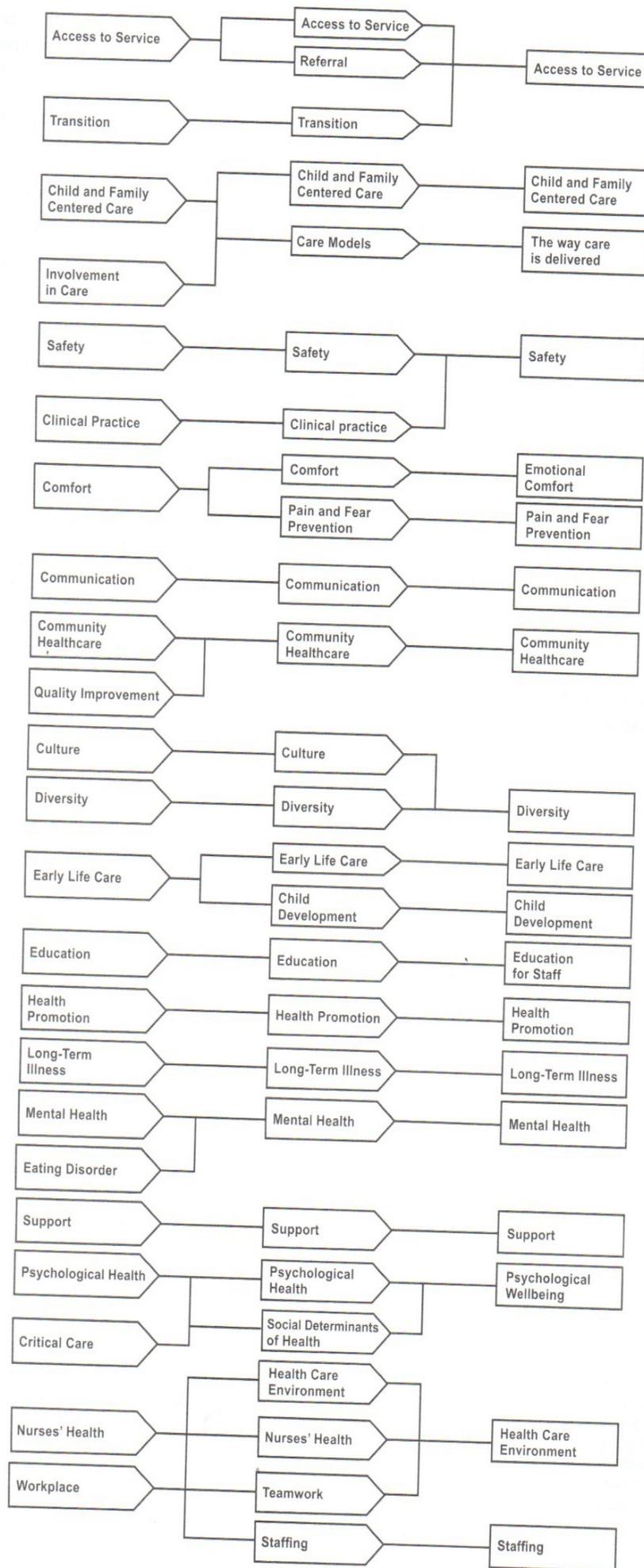
Fig. 2 This figure illustrates a three-step data analysis process of themes generated from survey statements. The analysis was a back-and-forth process in which themes were merged, split, or renamed. For instance, the theme 'Comfort' was split into 'Comfort' and 'Pain and Fear Prevention' in step 2. In step 3 'Comfort' was changed to 'Emotional Comfort' to clarify the theme's content.

consultation, iterative reviews, and revisions of the questions by the phase 1 workshop participants, researchers, and consumer advocate experts. Research Electronic Data Capture (REDCap) was used to manage the survey (Harris et al., 2009). The online survey was distributed through the Health Service social media pages, a WA parent support organization electronic newsletter, consumer groups, and Health Service staff email lists including medical doctors, nurses, and allied health professionals. At the end of the survey, participants were invited to register their interest in attending the phase 3 consensus workshop or to contact the researchers if they would like further information.

All survey responses were transferred into NVivo 12.6 (QSR International, Massachusetts) and data analysis was performed in three steps. *Step 1*, a direct content analysis (Hsieh & Shannon, 2005) was undertaken for each of the five survey questions by one of the authors using themes and sub-themes identified in the scoping review (Mörelius, Foster, & Gill, 2020). Nine new themes were created for statements that did not fit the predefined themes, for example 'community healthcare', 'diversity', and 'mental health' (Fig. 2). *Step 2*, themes for each of the five survey questions, were reviewed, discussed, and revised by three of the authors (Fig. 2). *Step 3*, themes were merged across the survey questions (see example in Table 2), reviewed, discussed, and summarized to reach consensus by four of the authors. The themes were finally reviewed by a fifth author and two consumer advocates, resulting in minor clarifications and name amendments of the themes (Fig. 2).

Phase 3, consensus workshop

Participants were recruited through the survey, and via nursing research youth and consumer advisory groups and Health Service staff email lists. The workshop was purposely held on a Saturday to enable adolescents and parents/guardians to attend. Prior to the workshop, registered participants ($n = 28$) were allocated to one of four tables with separate tables for adolescents, parents/guardians, and healthcare professionals. This separation was made to enable adolescents and parents to be able to talk openly without being influenced by healthcare professionals and so adolescents could make their opinions heard without involvement from adults. Each table was facilitated by one of the researchers. Themes identified from the survey were printed on A4 cards in different colors for each table to facilitate discussions and establish a prioritized list of themes. Explanations of the themes and examples from the survey responses were provided on the back of the cards. Spare blank cards were available to create new themes.

The workshop was conducted in four steps aligned with the modified JLA PSP workshop process as sequential stages of consensus building (Bowen et al., 2009) and included mid-morning, lunch and early afternoon breaks. The four steps included: *Step 1*, initial review and discussion about the research themes identified from the survey in small groups. A table facilitator ensured that positive or negative notes were

made next to each theme to determine the small groups' order of theme priority. Any new themes identified were noted by the table facilitators for discussion with the whole group in step 2. Each table facilitator was provided with facilitation guidelines before the workshop and used various facilitation skills to ensure participants were encouraged to voice their opinions openly and given the opportunity to equally share their experiences. *Step 2*, whole group discussion of feedback from step 1. Table facilitators summarized the main key points around themes discussed and shared these back to the whole group. Discussions included whether specific themes should be combined, or if new themes should be established. Participants who felt strongly about combining themes or establishing new themes were invited to provide their reasoning to the whole group. *Step 3*, small group prioritization of themes descending from 1 to 16. Using the theme cards (including the new/combined themes), small groups established a prioritized list of themes. Table facilitators recorded the ranked order of the themes. This list was then handed to the lead facilitator of the consensus workshop, who combined the priorities from all tables and established a list to be prioritized in step 4. In *Step 4*, a whole group open discussion was held to provide participants with an opportunity to contribute to the overall ranking on a top ten priority list of themes. Theme cards were displayed to the whole group to reflect and discuss the themes with the aim of agreeing on a top ten list. For instance, the adolescents strongly advocated for 'long-term illness' in favor of 'early life care'. Following a voting process consensus was reached on the theme ranking. Facilitators and consumer advocates did not vote.

Results

Planning workshop

The workshop was held in August 2019. Participants were nine adolescents, eight parents/guardians, five nurses, three medical doctors, and one social worker (Table 3). The workshop participants agreed with the themes identified in the scoping review and highlighted the need for additional areas such as, impact on daily life, transition of care, and community-, school- and primary healthcare. They also confirmed that the main gap was lack of consumer perspectives.

Survey

The online survey was open from October 2020 until January 2021. A reminder was sent once to healthcare professionals via email. In total, 232 persons responded to the survey (see characteristics in Table 3). The majority (45/86) of parents/guardians had two children (range 0–5+). Parents reported that most of their children were in the age group 6–12 years (range 0–18), six were Aboriginal and/or Torres Strait Islander, and one had applied for asylum/refugee status in Australia. The survey responses included 911 statements. The three-step analysis resulted in 19 themes (Fig. 2).

Consensus workshop

A one-day face-to-face consensus workshop was conducted in March 2021. A total of 19 participants attended: four adolescents, eight parents/guardians, and seven nurses (Table 3). A further nine registered participants were unable to attend due to sickness or other responsibilities.

Participants made some changes to the themes during the workshop (Table 4). 'Mental health' and 'Psychological wellbeing' were merged into one theme, and 'Child development' and 'Community health care' were merged into one theme. 'Emotional comfort' and 'Support' were merged and renamed to 'Practical and emotional support'. 'Long-term illness' was renamed to 'Living with a long-term condition'. Finally, participants re-installed the theme 'Transition'. This resulted in 16 final themes that were ranked from 1 to 16.

Table 2

Example of data analysis for the theme Communication across the five survey questions.

Survey question	Statement
1	"Communication with children; empowering children and young people to understand their own health".
2	"Better communication between primary care and tertiary services"
3	"Communication skills training and training on how to educate parents re the baby, child, or young person's condition".
4	"How inadequate staffing numbers impact on patient care and the ability to interact with families effectively".
5	"Children and young people are heavily relying on computers and social media to access information, communication, and learning. Whilst we are giving these students access to information and organizations, many young people are struggling to make that initial contact with a support person as they are reluctant to speak (due to many factors). It would be worth investigating in how we can make it more friendly to encourage open communication with this technologically advanced Generation".

Table 3

Characteristics of participants in the planning workshop, survey, and consensus workshop.

	Participants		
	Planning Workshop n = 26	Survey n = 232	Consensus Workshop n = 19
	n (%)	n (%)	n (%)
Adolescent 14–18 years	9 (34.6)	8 (3.4)	4 (21.0)
Parent/guardian	8 (30.7)	86 (37.0)	8 (42.1)
Community member	0 (0)	3 (1.3)	0 (0)
Healthcare professional	9 (34.6)	135 (58.2)	7 (36.8)
Nurse/midwife	*5 (55.5)*	*103 (76.3)*	*7 (100)*
Allied health	*1 (11.1)*	*3 (2.2)*	*0*
Medical doctor	*3 (33.3)*	*23 (17.0)*	*0*
Other	*0 (0)*	*6 (4.4)*	*0*
Gender			
Male	*7 (26.9)*	*15 (6.5)*	*2 (10.5)*
Female	*19 (73.0)*	*215 (92.7)*	*17 (89.5)*
Prefer not to say	*0 (0)*	*2 (0.8)*	*0 (0)*
Aboriginal and/or Torres Strait Islander origin	0 (0)	3 (1.3)	1 (5.3)
Culturally or linguistically diverse background	5 (19.2)	53 (22.7)	4 (21.0)

The top ten research priorities with summary of the content and illustrating sample quotes from the survey are outlined in Table 5. Themes ranked 11–16 were: 'Child and family centred care', 'Education for staff', 'Staffing', 'Health promotion', 'Pain and fear prevention', and 'Healthcare environment'.

Discussion

This study identified and prioritized a top ten list of research priorities for pediatric and child health nursing from the perspectives of adolescents, parents/guardians, and healthcare professionals in WA. The final top ten research priorities were decided in agreement between consumers and nurses resulting in a combined agreed priority list, an achievement that has not always been possible when targeting both groups at the same time (Taylor et al., 2020; Tume et al., 2020). 'Access to service' was the highest ranked theme. There is a need to continue to explore ways to enhance tertiary services for families living in metropolitan, regional, rural, and remote areas (Sivertsen et al., 2020) and to decrease barriers for access to timely and appropriate level of care (Taylor & Salyakina, 2019). Moreover, we need to know more about what nurses can do to make access to service a more streamlined process thus reducing the amount of time spent without access to the right care level, and ensuring children and families have the right support while waiting for referral.

This project started with a discussion about the research themes identified in a scoping review of eight pediatric nursing research priority setting projects published 2008–2019 (Mörelius, Foster, & Gill, 2020). Four themes from the scoping review were also identified in the current top ten list. This shows that the themes 'Mental health and psychological wellbeing' (priority 2), 'communication' (priority 3), 'living with a long-term condition' (priority 8), and 'safety' (priority 9) remain of high research importance for adolescents, parents/guardians, and healthcare professionals. According to WHO (2021), mental health conditions are increasing in children and youth worldwide. Approximately 20% have a mental health condition and suicide is the second leading cause of death in young adults (WHO, 2021). Psychological difficulties start early in life, for instance, a recent meta-analysis shows that infants born extremely preterm have greater overall risk for psychological difficulties than infants born full-term (Mathewson et al., 2017). Furthermore, stress during the pregnancy increases the risk of preterm birth (Staneva et al., 2015). More research is needed to find strategies for nurses to prevent mental health issues and enhance psychological well-being for children and adolescents.

New themes not identified in the scoping review (Mörelius, Foster, & Gill, 2020), were created during the analysis process and were ranked among the top ten priorities. These themes were 'Child development and community health care' (priority 5); 'Diversity' (priority 6); 'Practical and emotional support (priority 7); and 'Early life care' (priority 10). In particular, the diversity theme resonates strongly with the Convention on the Rights of the Child, in that children should be protected against all kinds of discrimination (United Nations, 1989). Aspects such as gender-identity, sexuality, social class, religion, disability, and appearance (Muirhead et al., 2020) could be more pronounced in nursing research (Patil et al., 2018) to increase equity, transferability and generalizability. Moreover, diversity is a research area in itself since being part of socio-culturally marginalized groups is associated with more chronic health conditions, psychological distress, and absence from school (Robards et al., 2020). In times of increased world migration, excluding families from research studies because of language barriers may hinder both participant recruitment (Mörelius, Olsson, et al., 2020) as well generalizability of findings. Practicalities such as using interpreters and translating instruments into different languages can be a research barrier due to additional costs, extra time required and lack of guidelines (Maneesriwongul & Dixon, 2004; Wong et al., 2019). Moreover, how and when to include interpreters in qualitative research needs careful consideration when planning a project (Shimpuku & Norr, 2012) to ensure rigor (Wong et al., 2019). This priority setting study can be used to inform funders that interpreters and translation of instruments are important budget items that facilitate inclusiveness in research.

'Transition' was added as a new theme during the consensus workshop (priority 4). Traditionally, most studies in child and adolescent healthcare have focused on the transition from pediatric to adult healthcare, a process that can be experienced as a dramatic culture shift by young people (Broad et al., 2017). A recent review showed that a structured transition process from pediatric to adult care, can improve adherence to care, quality-of-life, and disease-specific measures (Schmidt et al., 2020). However, current studies provide low level of evidence and limits the strength of evidence in this area (Campbell et al., 2016; Schmidt et al., 2020), supporting the need for more research. The theory of transition includes a passage from one condition, phase, or status to another (Meleis et al., 2000). Thus, this is a broad theme with many opportunities to expand the research to for instance, transitioning from hospital to community healthcare.

The themes ranked 11–16 did not progress to the final top ten list but remain important. Some of these themes were viewed as already being well researched albeit lacking, which was the need to use a systematic process for translation and implementation of new evidence. It has been widely reported that it can take on average 17 years for research to be incorporated into routine clinical practice (Bauer et al., 2015). Many factors influence knowledge uptake and using an implementation science approach is increasingly being recognized as key to success. An important knowledge translation enabler is the inclusion of end users (Curtis et al., 2016) throughout the research process (Wensing & Grol, 2019).

Table 4

Changes made to themes during the consensus workshop.

Theme	New theme
Mental health Psychological wellbeing	Mental health and psychological wellbeing
Child development Community health care	Child development and community health care
Emotional comfort Support	Practical and emotional support
Long-term illness	Living with a long-term condition Transition

Table 5

Final top ten ranking after consensus workshop with summary of the content and illustrating sample quotes from the survey.

Priority	Research theme	Summary of the content	Sample quote
1	Access to service	This theme included issues such as timely access to service; appropriate local service; referral pathways; updated resources, programs, and booking systems; and reducing time out of school for attending appointments.	"It seems there is no help until it's a crisis rather than much earlier on".
2	Mental health and psychological wellbeing	This theme focused on looking beyond the medical focus of care and how nurses can better decrease stress and improve psychological support for children and families.	"Mental health, it impacts every single aspect and is the difference between quality of life."
3	Communication	This theme included clinical handover; consistency; communication techniques; care plans; and communication between different parties such as children and staff, staff and staff, service and service.	"Communication definitely reduces fear and frustration. If there is a delay, let the family know. If there is a problem, tell the family - be transparent."
4	Transition	This theme reflected transition from pediatric to adult services; from hospital to home; from tertiary to regional services; as well as support to new parents.	"Collaborative working between acute and community services for transition of care."
5	Child development and community health care	This theme included, how nurses can help children with developmental delays; support children to stay out of hospital; increase attendance through local community-based services; and nurse-led clinics.	"What nurses can do to help babies and children with developmental delays, particularly when they are on various services."
6	Diversity	This theme included that research was needed around and in collaboration with families related to their culture, disability, family structures, and geographic location. Social determinants of health; use of interpreters; and refugees were also highlighted.	"Gender diversity and how we can better support these young people in school communities."
7	Practical and emotional support	This theme was about quality of experience for children and their families and how nurses can better provide support for the child and the family.	"How nurses can be most effective in caring for the entire family not just the admitted child."
8	Living with a long-term condition	This theme included the importance of improving the experience for children and adolescents living with a chronic disease, condition, delay, or disability; health literacy; teamwork; and relationships.	"Conditions outside the box."
9	Safety	This theme was about how nurses can create a safe physical, psychosocial and cultural environment for children and their families in the healthcare system.	"Environmental impact of clinical care improving safe management of unwell children".
10	Early life care	This included research on neonatal care and psychosocial needs of infants in the first 1000 days.	"A focus on the very earliest years of a child during which the brain is developing and forming pathways and connections that will affect their mental health, the way they interact with others, their ability to learn, for the rest of their lives".

The strength with this priority setting includes the use of a systematic and transparent three-phase PSP. This method has previously been used within WA, the facilitator running the workshops has three decades of experience working with consumers, and the end users or consumers and health professionals have been engaged throughout the whole process. For adolescents and parents to feel safe and heard during the consensus workshop, they were grouped at separate tables from each other and the health professionals. Many of the participants were also familiar with each other and the facilitators from the planning workshop. Another strength with this study was that the number of participants was higher or like previous pediatric nursing research priority settings (Brenner et al., 2014; Green et al., 2014; Raman et al., 2021; Ramelet et al., 2012; Tume et al., 2014; Tume et al., 2015; Tume et al., 2020; Wilkes et al., 2013; Wilson et al., 2010).

Application to practice

Identification of the top ten priorities for pediatric and child health nursing research is just a start. The importance is now to create research questions aligned to the themes to ensure that the voices of consumers and other stakeholders are acknowledged in upcoming research. Dissemination to researchers, healthcare organizations, and external funders, will enable planning and future research to be coordinated and directed to areas of high priority for adolescents, parents/guardians, and health professionals in WA.

Limitations

One limitation is the focus on one state in Australia which may limit the transferability. However, WA is the largest state and includes both metropolitan areas and rural areas. An additional limitation is that we had only a few responses from community members without connection to the Health Service. It may be the limited recruitment strategy used or community members did not perceive the survey of relevance or interest. More focused targeting

might be needed if the intention is to include community members in the future.

Conclusions

During a three-phase PSP process, 19 research themes were identified that were discussed and ranked during a consensus workshop with adolescents, parents/guardians, and nurses in WA. The final top ten list of research themes for pediatric and child health nursing included: access to service; mental health and psychological wellbeing; communication; transition; child development and community child healthcare; diversity; practical and emotional support; living with a long-term condition; safety; and early life care. The research themes can now inform planning for future research to be directed to areas of high priority for adolescents, parents/guardians, and health professionals in WA.

Funding sources

Ethics

Approval was received from the Health Service Human Research Ethics Committee (RGSS0000003684) and reciprocal approval was received from Edith Cowan University and Curtin University (2020-01798 and HRE2020-0451).

Declaration of Competing Interest

The authors have nothing to declare.

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