

Primary Caregiver and Youth Perspectives On Using An Inpatient Portal For Pain Care

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There are no conflict of interests by all authors

INTRODUCTION

Hospitalized children experience pain that is inadequately assessed, undertreated and associated with wide-reaching adverse outcomes¹. Child and family engagement in care improves care quality and safety². Involving children and families in pain care via a patient portal linked to hospital electronic medical records could improve engagement, satisfaction and outcomes for hospitalized children and families.

AIM

Examine perspectives of primary caregivers of hospitalized children and of hospitalized youth from a single tertiary pediatric setting about using an inpatient portal for pain care.

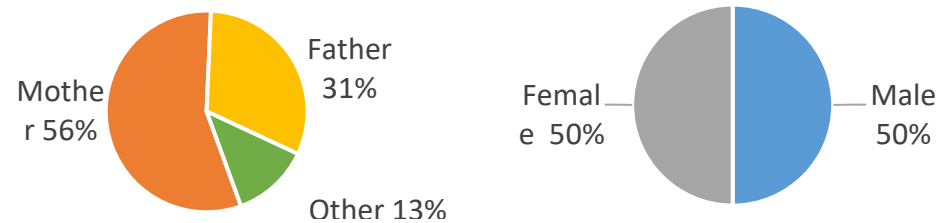
METHODS

Qualitative descriptive design using semi-structured interviews and reflexive content analysis³. Information Power guided sample size⁴.

RESULTS

PCGs n=14

Youth n= 4



1. CONNECTING & SHARING PAIN KNOWLEDGE

2. PRESERVING ROLES

1.1 Deep Insights Into Pain Experiences

Participants wanted to use a portal to view & contribute pain data. They are experts in their/their child’s pain & best able to report momentary pain symptoms. Functionality to track pain & recovery was important. A top priority was for functionality that allowed children & families to report broad symptoms including pain’s physical, psychological & functional impacts.



2.1 Complementing Clinician Roles



Participants thought a portal would enhance communication with clinicians. But also worried about how a portal could burden clinicians if not designed or implemented appropriately. They strongly advocated that portals should not replace human interaction integral to pain care.

1.2 Transparent Information For Empowerment



Participants wanted transparency through real time access to information in the portal including their care plans & other reliable pain-related resources. This was this was important to help them make informed decisions, enhance engagement & offer a sense of control

2.2 Protecting Parental Roles

Primary caregivers explained needing to balance portal use & preserving & protecting their inherent caring roles. Their priority was their child. Because hospitalized children are unwell & families are in a state of crisis, participants suggested children & families need time to come to terms with the clinical situation & settle in before accessing & using a portal



3. USER CENTRED DESIGNS



Participants advocated for portal designs that were simple, intuitive, with robust data security & that could be tailored based on the end-users’ age, developmental stage, clinical situation & health & digital literacy. They shared mixed feelings about push notifications to remind them to record pain information

CONCLUSION

Findings outline consumer recommendations for portal configurations that deeply engage and empower children and families in pain care through multidirectional knowledge sharing, supporting clinician and caregiver roles without burdening or replacing human interaction implicit to care. Further research should measure the impact of portals on outcomes and explore clinician’s perspectives.

ACKNOWLEDGMENTS

We gratefully acknowledge participating parents & youth. NP is the recipient of The Melbourne Research & Be Sweet to Babies Scholarships. She is also the recipient of the Vera Scantlebury Brown Child Welfare Memorial Trust & Australian Nurses Memorial Centre Prince Henry’s Affiliates Scholarship & PICH travel grants. These funders have no role in the design or conduct of the study.

REFERENCES

