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Smart Discharges for Children: Exploring Healthcare Providers' Perspectives of the Pediatric Discharge Process in Uganda

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Abstract

The burden of childhood mortality continues to be born largely by low-and middle-income countries.

The critical post-discharge period has been largely neglected despite evidence that mortality rates during this period can exceed inpatient mortality rates. However, there is a paucity of data on the pediatric discharge process from the perspective of the healthcare provider. Provider perspectives may be important in the development of an improved understanding of the barriers and facilitators to the improving the transition from hospital to home.

Objectives

To explore healthcare providers' and facility administrators' perspectives of the discharge process with respect to: (1) current procedures, (2) roles of key personnel, (3) barriers and facilitators to improvement, (4) areas for potential change, and (5) the importance of discharge planning.

Design

A qualitative exploratory approach using focus groups (14) and in-depth interviews (7).

Setting

This study was conducted at seven hospitals providing pediatric care in Uganda.

Results

Current discharge procedures are largely based on hospital-specific protocols or clinician opinion, as opposed to national guidelines. Some key barriers to an improved discharge process included caregiver resources and education, critical communication gaps, traditional practices, and a lack of human and physical resources. Teamwork and motivation to see improved pediatric transitions to home were

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3 identified as facilitators to implementing the ideas for change proposed by participants. The need for a
4
5 standardized national policy guiding pediatric discharges, implemented through education at many
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7 levels and coupled with appropriate community referral and follow-up, was broadly perceived as
8
9 essential to improving outcomes for children.
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12 13 Conclusions

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16 Although significant challenges and gaps were identified within the current health system, participants'
17
18 ideas and the identified facilitators provide a significant basis from which change may occur. This work
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20 can facilitate the development of sustainable and effective interventions to improve post-discharge
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22 outcomes in Uganda and other similar settings.
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Strengths and Limitations of this Study (up to 5 bullet points)

- This study represented seven regions in Uganda and included both private and public facilities
- This study may have limited generalizability to other countries, particularly those outside of sub-Saharan Africa
- Although some focus groups were at times small, the high degree of interest and participation provided deep insights into barriers faced by facilities, health workers and caregivers
- The lack of the caregiver perspective limits some of the conclusions of these data
- The information gathered through these qualitative interviews can provide critical information in designing effective interventions to improve the pediatric discharge process

Funding Statement

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Competing interests

The authors declare that they have no competing interests

Background

The third of 17 Sustainable Development Goals commit the world to “ensure healthy lives and promote well-being for all at all ages” by the year 2030, a key aspect of which is decreasing under-five mortality.(1) However, the burden of under-five mortality continues to be born largely by low-and middle-income countries (LMICs), with half of the world’s total under-five deaths occurring in Sub-Saharan Africa alone.(2) Over the past several decades, significant effort has been made to address the diagnosis and treatment provided during acute care, but care following hospital discharge has been largely neglected in research, policy, and practice.(3) The post-discharge period represents a critical time for a child recently admitted for infectious illness; mortality post-discharge can be equal to or even exceed inpatient mortality.(3) In Uganda, a recent study found that approximately 5% of under-five children who have been hospitalized for infectious illness died in the six months following discharge.(4) Evidence from a recent proof-of-concept study in Uganda, known as *Smart Discharges*, demonstrated improved outcomes following discharge through an educational intervention and community-level referrals for follow-up.(5) Discharge education and follow-up after discharge appear to be critical components necessary to improve the long-term survival of children admitted with serious infectious illness.(5) However, little is known regarding the facilitators and barriers to adoption within the Ugandan health system. Understanding the current discharge processes in Ugandan hospitals and the challenges they face is a necessary step prior to further adoption and scaling-up of such processes. Therefore, within the context of severe pediatric infectious illness, this study aimed to explore healthcare providers’ and facility administrators’ perspectives of the discharge process, with respect to: 1) current procedures, 2) roles of key personnel, 3) barriers and facilitators to improvement, 4) areas for potential change, and 5) the importance of discharge planning.

Methods

Design

This qualitative exploratory study included focus groups (FGs) and in-depth interviews with key professional stakeholders in order to explore the current pediatric discharge process within the Ugandan health care system, an area that has yet to be extensively studied. This study design is ideal for understanding and describing the gap in this area of research, creating a basis upon which further research may build.

Patient and Public Involvement

Patients and public were not involved in the development of the research question or outcomes.

Study Setting

The study was conducted at seven sites across Uganda, including five public, government-funded hospitals, and two private not-for-profit hospitals. Government-funded hospitals included: Lira Regional Referral Hospital (LRRH), Gulu Regional Referral Hospital (GRRH), Jinja Regional Referral Hospital (JRRH), Masaka Regional Referral Hospital (MRRH-Masaka), and Mbarara Regional Referral Hospital (MRRH-Mbarara). Private not-for-profit hospitals included Holy Innocents Children's Hospital (HICH) in Mbarara and Kisiizi Hospital in Rukungiri district. The hospitals represent the regional distribution of major hospitals across Uganda. Hospitals varied with regard to bed capacity, number of annual pediatric admissions, and numbers of staff (**Table 1**).

Table 1: Hospital Demographics

Hospital site	Approximate total bed capacity	Number of Pediatric Beds	Number of Children age 0-5	Pediatric Physicians	Pediatric Nurses

			years admitted annually*		
GRRH, Gulu	397	32	5,774	9	31
JRRH, Jinja	408	50	7,559	8	17
MRRH, Masaka	330	45	4,876	7	7
MRRH, Mbarara	600	79	2,398	17**	17
HICH, Mbarara	60	60	5,623	5	21
Kisiizi hospital, Rukungiri	250	38	1,326	5	11
LRRH, Lira	346	70	3,428	4	20

*Average of total admissions aged 0-60 months for the three years: 2015, 2016, 2017

**Includes 9 Senior House Officers (Masters of Pediatric Medicine students who attend to patients as part of their training requirement but are not employees of Mbarara Regional Referral hospital)

Sampling and Inclusion Criteria for Focus Groups and In-Depth Interviews

Site participants were recruited using purposive sampling. Frontline pediatric providers (i.e., nurses and doctors) who had worked in the pediatric ward for at least two months preceding the time of data collection were eligible FG participants. Hospital administrators were considered eligible for participation in the in-depth interviews if they were currently involved in clinical administrative work and had some degree of oversight for the pediatric ward. Initial contact with study participants was through each respective hospital's human resources department.

Data Collection

Interviews and FGs were conducted from April to July 2018. Fourteen FG discussions—seven with nurses and seven with physicians/clinical officers—were conducted across the seven study sites, together with seven in-depth interviews with hospital administrators from six study sites. The hospital administrator at one study site was unavailable during the interviewing period and was thus excluded. Each FG largely

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2
3 consisted of 3-5 participants. FGs and in-depth interviews were conducted by a trained research
4
5 assistant using semi-structured interview guides (**Additional file 1**). Nursing FGs lasted approximately
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7 35-75 minutes, clinician FGs approximately 50-80 minutes, and in-depth semi-structured interviews
8
9 approximately 15-50 minutes. All interviews and FGs were audio recorded following participant
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11 permission.
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14 15 Ethics

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18 Ethical approval was obtained from the research ethics boards at the University of British Columbia
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20 (H18-00403) and Mbarara University of Science and Technology (MUREC 1/7). All focus groups and in-
21
22 depth interviews were conducted in a private hospital meeting room after obtaining written informed
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24 consent from participants. Participants were provided with an honorarium of 25,000 Ugandan Shillings
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26 (approximately \$7 USD).
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31 Analysis

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35 Focus groups and in-depth interviews were recorded and transcribed verbatim by two interviewers and
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37 then spot-checked for consistency by another member of the investigative team. Transcripts were then
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39 analyzed using NVivo 11 software (QST International, Cambridge, MA). Mind-mapping, coding, and node
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41 structures were identified and reviewed by two team members. Coding of the data aimed to identify
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43 categories and linkages and to explore patterns. Relationships generated between key themes are
44
45 depicted using a conceptual framework (**Error! Reference source not found.**), from which further sub-
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47 themes emerged (**Figure 2**).
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Figure 1: Conceptual Framework

Figure 2: Discharge Theme Map

Results

A total of 58 participants, with wide ranges of experience and training, contributed to the 14 FGs and seven in-depth interviews (**Table 2**). Nursing FGs included 28 nurses holding either certificates or diplomas. Nurses had, on average, more practical experience in months (M=116.7, SD= 90.7) compared to that for all participants (M=37.1, SD= 82.9). Clinician FGs included 23 clinicians/interns with significantly less practice experience than their nursing counterparts (M= 24.1, SD= 38.2). Six of the seven hospital administrators held a Masters of Medicine, with most having between 2 and 8 years of administrative experience (M=6.7, SD=11.3).

Table 2: Participant Demographics

Hospital	Healthcare Worker	Number of Participants	Gender (% female)	Age Group	Education
GRRH, Gulu	Nursing	4	100%	1 (25-33)	1 (certificate)
				1 (34-41)	3 (diploma)
				2 (42-49)	
GRRH, Gulu	Clinician	4	25%	1 (18-25)	3 (intern)
				2 (26-33)	1 (MBChB)
				1 (42-49)	
GRRH, Gulu	Administration	1	100%	(42-49)	MMed
JRRH, Jinja	Nursing	5	100%	3 (26-33)	2 (certificate)
				2 (34-41)	3 (diploma)
JRRH, Jinja	Clinician	4	0%	2 (26-33)	4 (intern)
				2 (34-41)	
JRRH, Jinja	Administration	2	50%	2 (42-49)	1 (diploma)

					1 (MMed)
MRRH, Masaka	Nursing	3	100%	1 (26-33) 1 (34-41) 1 (42-49)	1 (certificate) 2 (diploma)
	Clinician	3	0%	1 (18-24) 1 (26-33) 1 (34-41)	3 (intern)
	Administration	1	0%	(42-49)	MMed
MRRH, Mbarara	Nursing	4	100%	2 (18-25) 1 (26-33) 1 (42-49)	3 (certificate) 1 (diploma)
	Clinician	4	75%	3 (26-33) 1 (34-41)	4 (MBChB)
	Administration	1	0%	(34-41)	MMed
HICH, Mbarara	Nursing	4	75%	1 (18-25) 3 (26-33)	2 (certificate) 2 (diploma)
	Clinician	3	33%	3 (26-33)	3 (MBChB)
	Administration	1	0%	(34-41)	MMed
Kisiizi Hospital, Rukungiri	Nursing	3	66%	1 (18-25) 1 (26-33) 1 (34-41)	1 (certificate) 2 (diploma)
	Clinician	2	0%	1 (26-33) 1 (34-41)	2 (intern)
	Administration	1	0%	>50	MMed
LRRH, Lira	Nursing	5	100%	2 (26-33) 1 (34-41) 2 (42-49)	5 (diploma)
	Clinician	3	33%	3 (26-33)	2 (intern) 1 (MBChB)
	Administration	-	-	-	-

Key themes

Five a-priori themes became the framework for initial analysis, from which sub-themes and concepts emerged, expanding the coding scheme to bring further clarity and understanding to the pediatric discharge process (**Figure 2**).

Current Procedures

Participants described typical daily activities in the pediatric wards, including ward rounds, seeing outpatients, admitting, treating, and discharging children. Participants generally stated that they were unaware of written guidelines or policies regarding discharge processes for children admitted with infectious illnesses. Although the Uganda Clinical Guidelines 2016(6) were occasionally mentioned, participants largely cited either hospital-specific Standard Operating Procedures (SOPs) for specific disease processes, implied institutional policy, or departmental culture as the basis for current discharge practices. As one administrator stated, *"I think really they [standards/guidelines] are implied, they are not explicit that they are written down, and that's where the gaps are"* (Admin 5). These implied criteria are based on assessed clinical improvement. Health professionals in the FGs noted that mothers with more schooling had greater understanding of the importance of follow-up for their child.

Current pediatric post-discharge follow-up procedures were described, with one administrator noting that the only community-level, post-discharge follow-up that occurred was that undertaken by research studies. Clinicians at one of the private hospitals stated that one nurse traveled each Saturday to different regions in the hospital's catchment area to visit malnourished children recently discharged; however, all other children were given a follow-up date at the discharging hospitals outpatient clinic. Participants consistently identified follow-up clinics for specific chronic diseases such as HIV, tuberculosis (TB), malnutrition, sickle cell, and cardiac conditions. Referral to these chronic diseases-

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3 specific clinics are common and often stated to be part of guidelines; however, patients admitted for
4 acute infectious illness are given a post-discharge review date dependent upon clinician judgement
5 determined on an individual basis and highly reliant upon the many compounding factors (such as
6 severity of illness, condition at discharge, etc.) involved in the child's illness. Most participants stated
7 they did not give review dates to all children with infectious illnesses, and review dates, when given,
8 were scheduled in an outpatient clinic (usually the discharging facility) at two to three weeks post-
9 discharge.
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20 Barriers/Challenges

21 *Socioeconomic Cost to Patients and Families*

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24 Socioeconomic issues such as finances and transportation play a role in all aspects of health and health
25 seeking, not only for discharge and follow-up care, but also in timely initial treatment, readmission, or
26 referral to a higher level of care. Clinicians talked of caregivers reaching the hospital with a child too sick
27 to save: *"They will tell you they have taken like three days because they were looking for money to meet*
28 *their transport costs"* (Clinician 23). Private hospital employees cited challenges related to bills incurred.
29 Parents desperate for care bring a child to a private hospital, but, upon discharge, they are unable to pay
30 their bill or decide to forego any post-discharge treatment due to finances.
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43 Both private and public hospitals frequently talked about discharging children prematurely or against
44 medical advice, often due to the caregiver's request. This decision was largely related to the financial
45 burden that families experience in caring for their hospitalized child or due to the need to care for other
46 children at home. *"Sometimes you want to keep the patient for a longer time but they are unable, they*
47 *are unwilling to stay. So... you make a decision that is not called for and you discharge them*
48 *prematurely"* (Clinician 1).
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3 The financial state of the family is also influential when a clinician recommends medication to be taken
4 at home or that a child be followed-up after discharge. Regional Referral Hospitals (RRHs) in Uganda are
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6 few and yet serve large catchment areas, both in terms of geography and population, making follow-up
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8 at this level of facility very difficult for patients and facilities. It is common practice to send a child home
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10 with oral antibiotics; however, medications are often not free and thus are sometimes not purchased,
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12 leaving children vulnerable to subsequent deterioration or recurrence of infection. Whether families
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14 purchase these medications is not known unless they attend a follow-up appointment or are readmitted
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16 to hospital. *“There are really mothers even if Ampiclox [antibiotic] is two thousand [Ugandan Shillings;
17
18 about \$0.50 USD], they will not buy it; they don't have the money”* (Clinician 21). One administrator talks
19
20 of the many interwoven socioeconomic barriers to complete care for the child, saying: *“there are always
21
22 issues of resources and transport... if the health facility that you want the child to be seen at is far away,
23
24 then they are unlikely to go there because mostly the people we treat are very poor so they can't afford
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26 to come back or to buy the medicines or even to buy the basic things like soap for hand washing. Or they
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28 don't have access to clean water”* (Admin 7).
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34 35 *Tradition and Culture*

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38 Traditional and cultural practices and family roles are important aspects of health, including a child's
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40 discharge and follow-up. Although a mother may wish for her child to remain admitted, purchase
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42 medications, or attend a follow-up appointment, pressure from the father or male decision-maker may
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44 limit her ability to complete all necessary aspects of care. Fathers often hold the finances, thus directly
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46 affecting whether the mother can complete a follow-up appointment or obtain medications upon
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48 discharge. Elders (such as the mother-in-law of the mother) also influence health-seeking behaviour and
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50 may lead a caregiver to either forego formal medical care or supplement with traditional healing
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52 practices, which may itself hinder a child's recovery or even precipitate further illness. Traditional
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3 healers at times conduct aseptic surgical procedures, precipitating further illness and infection. "...they
4 have this pressure at home and they are like no this condition will not be treated by those medications; if
5 we did these cuts to the child's body, they will help... like there are those cases we receive here; the child
6 has been having diarrhoea, he is dehydrated, he is not feeding. So this, in the community there, will be
7 interpreted as the child having 'ebiino' [false teeth]- that is why the child is not breastfeeding. Yet you as
8 a clinician, you know that this child is dehydrated and this is why the child has failed to breastfeed"
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12 (Clinician 1). Sometimes when health workers discharge a child prematurely, they knew that it was
13 because the family wanted to try cultural healing practices: "these common cases of upper respiratory
14 tract infections, from the hospital, they [go] for local tonsillectomy. One, two, three days the child is back
15 with severe anaemia, septicaemia, very sick" (Clinician 23).
16

17 *Lack of Hospital Resources*

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19 The issue of human resources largely equates to workload and the understaffing that is prevalent in
20 Ugandan medical facilities. Participants talk of a nurse working alone in a ward, how she cannot be able
21 to do all of the procedures, administer medications, and provide thorough teaching, and so, she will end
22 up prioritizing emergencies and each interaction may have lesser quality than she would have liked to
23 provide. Clinicians see large numbers of children each day and may, therefore, either prioritize cases or
24 allocate tasks to students. Many of the RRHs are teaching hospitals. One hospital stated that due to
25 inadequate staffing, medical interns and Senior House Officers (SHOs) in pediatrics usually ran the
26 pediatric ward. Busy hospitals mean that the most experienced are managing the emergencies, leaving
27 junior clinicians or students- those least experienced- to run the wards and manage discharges.
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30 Issues of inadequate physical resources include shortages of supplies and medications, lack of
31 investigatory capacity, lack of sufficient beds or hospital space, among other physical constraints present
32 in Ugandan pediatric wards. Participants from many hospitals stated that their hospital laboratory
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3 analyzer for measuring complete blood counts was out of commission, meaning that even simple
4 investigations often used to guide treatment and assess readiness for discharge had to be done from
5 generally unaffordable private laboratory facilities: *“At discharge, most of the diagnosis we make here,*
6 *we do them clinically because of lack of investigations. So, we usually discharge patients when we don't*
7 *know the real focus. And at times because we are just treating generally we might not have really*
8 *tackled the focus of the septicemia and the children usually come back”* (Clinician 16). Hospital bed
9 capacity also affects not only inpatient care, but also a child's discharge, as clinicians at times are forced
10 to discharge prematurely due to space constraints. It is common to see one bed with up to four pediatric
11 patients, each with differing conditions, *“...this one maybe has measles which has not shown up, this one*
12 *has acute watery diarrhoea, then this one has... you know, we are just infecting and not helping the*
13 *children”* (Clinician 10).

28 Ideas for Change

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32 Administrators, clinicians, and nurses brought forward ideas for change largely in relation to the many
33 barriers and challenges they had identified.

36 *Adequate Resources*

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40 Participants spoke to the need for adequate human and physical resources which would improve their
41 ability to investigate, diagnose, treat, and discharge children admitted for infectious illness. It was
42 acknowledged that families often do not purchase items such as discharge medications that are not
43 provided outside of the public system due to their socioeconomic status. Therefore, the common
44 perception was that public, government-funded facilities should be equipped with the necessary
45 supplies to treat a child and provide medications required upon discharge in order to ensure a full
46 recovery. Further resources not currently in place in many facilities were suggested as potentially
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3 beneficial, such as including a social worker as part of the discharge team and a ward telephone to be
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5 used for follow-up.
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7 8 *Standardization* 9

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11 Comprehensive, linked care was deemed necessary to improve current practices. A key aspect of
12
13 comprehensive care is strengthening the Ugandan referral system, which was stated to not function
14
15 optimally in its current state. Many participants envisioned a system in which, upon discharge, children
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17 could be connected to their local health centre or district hospital where they could be followed-up and
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19 referred back up to the RRHs if required. Referral both up and down the chain was identified to be a
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21 current difficulty in the system. *“Continuity of care from the hospital to the community; I think that is the
22
23 best way we can help these children of ours grow very well”* (Clinician 8). In-hospital care should not
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25 stand alone, but be integrated within a larger vision; according to participants, a holistic approach is key
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27 for lasting change and improved outcomes after discharge, including aspects of preventive and
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29 community measures such as immunization, sanitation, clean water, education, transport, and road
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31 improvement.
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37 Clinical pathways/guidelines for discharge, at both national and hospital levels, was considered of great
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39 importance to every health provider interviewed. National policy from the Ugandan Ministry of Health
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41 and other governing bodies influence what occurs in the medical system. Clinicians stated that having a
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43 well-designed, endorsed, national policy for discharge for RRHs would be essential to ensure uptake and
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45 standardization both within and between care facilities. However, change requires political will, so *“... if
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47 we don’t have a lot of buy-in or commitment from the Ministry of Health and support for them because
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49 we need resources, then it becomes difficult to expect facilities to implement it”* (Admin 7).
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53 It was emphasized that clinical pathways or guidelines implemented at the national level should be
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55 applicable to the realities observed at the hospital level, taking into consideration resource availability.
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3 Participants often talked of the importance of a pre-structured discharge form, wherein the discharging
4 clinician could easily fill in all required information to provide a holistic view of the child's health status
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6 along with the comprehensive plan for discharge and follow-up. With such a standardized discharge
7
8 pathway, the discharging clinician can better facilitate communication with families, the healthcare
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10 team, and communities. One clinician identified the possibility of a "discharge secretary", whose job
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12 would be to ensure that discharge forms are filled out in their entirety, complete with a clinician
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14 signature, to aid accountability that appropriate follow-up is made with lower-level health facilities and
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16 to ensure that a copy of the discharge form is retained for future reference and follow-up.
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21 22 *Education*

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25 The healthcare team bears the important role of health education: "...to see that they will not come back
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27 in the same situation again. Should it happen again, they will go for healthcare faster than they came
28
29 this time around. And if it happens to another child, they should be able to identify that this one is this,
30
31 and it doesn't need local herbs or anything, it needs to go to the hospital" (Clinician 3). One
32
33 administrator from a private hospital spoke of their hospitals move towards providing a discharge
34
35 summary in the local language to facilitate communication and reinforce the education provided by
36
37 health professionals. Going from individual caregiver education to the broader community level, one
38
39 clinician suggested that a small compulsory course on antenatal and child health be integrated into the
40
41 national education system: "Because every woman is a potential mother even a father. So, to know
42
43 certain basic, basic things, it will educate the whole nation" (Clinician 3).
44
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47
48 A common theme among participants was that continuous health worker training is required not only
49
50 for those working in hospitals, but also those working at lower level facilities and within communities, to
51
52 ensure that all parties are informed. Whatever protocol or guideline is put into place, they must be both
53
54 accessible in real-time and paired with appropriate training to ensure their relevance and applicability
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3 are optimally conveyed to the end-user: *“if you make the clinicians understand the contents of that*
4 *template, it can also increase its acceptability and its being put to use”* (Clinician 20). Once a change to a
5
6 standardized discharge protocol is developed and implemented, clinicians and administrators spoke of
7
8 the need to also include it into pre-service training (i.e., medical and nursing curricula).
9

10
11
12 Health worker education includes equipping and empowering professionals working in lower-level
13
14 facilities and communities to be able to receive discharged children in follow-up (down referrals), to
15
16 manage simple cases, and in so doing, take some of the burden off of RRHs. *“I would want to be able to*
17
18 *train and coach and mentor the health workers at the lower level to be able to carry some of this”*
19
20 (Admin 2). At the local level, Village Health Teams (VHTs) are members of each community who may be
21
22 trained and then utilized in follow-up for children recently discharged, assisting the caregiver with
23
24 identifying signs of further illness and reminding of the importance of follow-up appointments.
25
26

27 28 29 *Communication and Collaboration* 30

31
32 Caregivers are important members of the healthcare team; they are constantly with the child and are
33
34 often utilized by health professionals as a source of history, presenting illness, and treatment
35
36 progression. *“There is this saying that the mother is the best doctor because she spends most of the time*
37
38 *with her child”* (Clinician 22). The mother or caregiver ought to participate in determining the child’s
39
40 readiness for discharge as she is ultimately the one who will continue to care for the child upon
41
42 discharge. Communicating well with the caregiver from the beginning—from admission—may facilitate
43
44 an open and understanding relationship between the family and medical team and ensure that
45
46 caregivers are fully informed. A discharge form given to the caregiver outlining the inpatient treatment
47
48 and discharge instructions is common practice in Ugandan hospitals. The private hospitals both
49
50 mentioned a gradual transition to a computerized system which would include the retention of an
51
52 electronic copy of medical records, including the discharge form. This will aid in communication and
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3 continuity of care for those patients who do not bring their discharge form for follow-up visits or
4
5 readmissions.
6

7
8 Discharge as a team activity requires collaboration and clear communication. Key players identified in
9
10 the discharge team included the caregivers, clinicians, nurses, administration, and other health
11
12 professionals such as consultants, nutritionists, or physiotherapists involved in the care of the
13
14 hospitalized patient. Although participants spoke to the unlikely nature of being able to gather together
15
16 to discharge patients, this barrier was thought to be able to be mediated by strong communication
17
18 within the team and fulfilling one's professional role. Clinicians stated the value of nursing staff, noting
19
20 that nurses have thoughtful insights gained through the time spent assessing patients throughout their
21
22 shifts.
23
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26
27 Collaboration and communication at the community-level include inter-facility communication between
28
29 hospitals, lower-level health facilities and Village Health Teams (VHTs). Given that RRHs do not have the
30
31 capacity to follow up all discharged children, follow-up is an important community-level aspect of care.
32
33 Many participants thought that follow-up could be conducted by the health facility nearest the patient's
34
35 home or by the VHT. An added benefit to local follow-up is that these interactions are convenient times
36
37 to address broader public health issues affecting children, families and the communities at large, such as
38
39 immunization, hygiene, and other areas of health promotion and preventive medicine.
40
41

42 43 Facilitators

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45
46 Participants overall noted an attitude of teamwork, motivation, and interest in the discharge and follow-
47
48 up process as an important aspect of a child's health journey. Participants consistently referred to
49
50 themselves as a team working towards the common, shared goal of healthier patients, communities,
51
52 and society. *"... my team, they are willing, they have that desire to make sure that their patients*
53
54 *survive... most of them go over and above what is their call to serve those children... So I know they don't*
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3 *want them to go and die at home so the willingness to find a solution if they know somebody can do to*
4
5 *keep these children alive I know they would jump on it... the teams work with that passion to keep those*
6
7 *babies alive and grow to adulthood” (Admin 2).*
8
9

10 11 Importance of Discharge Planning

12
13
14 When asked about the importance of discharge planning, participants often spoke of preparation.

15
16 Discharge planning allows families and the healthcare team to prepare for a child to return to their
17
18 community. *“Its like preparation for this child to get back into the community... you can get to know how*
19
20 *to discharge this patient and how to help them when they get back into the community” (Nurse 22).* A
21
22 plan for discharge can allow the healthcare team to communicate early on with the family about a
23
24 pending discharge, allowing them time to coordinate issues such as transportation or purchasing any
25
26 medications required after discharge, thus ensuring the readiness of the family for the transition home.
27
28

29
30 Discharge planning allows for a consistent understanding and continuous evaluation of readiness for
31
32 discharge, which may help reduce premature or uncoordinated discharges that lead to deaths or
33
34 frequent readmissions and associated healthcare costs to both families and government facilities. There
35
36 was a recognized need to carefully manage children through to the discharge and even afterward, which
37
38 may be aided by a discharge plan. Often times for hospital staff, once a child is discharged, how a child
39
40 progresses afterwards can be forgotten without something specifically guiding a process for care post-
41
42 discharge.
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46 47 Discussion

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51 This study found that in Ugandan hospitals, current discharge procedures for children with infectious
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53 etiologies are largely based on hospital-specific protocol or clinician opinion, as opposed to universal
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55 guidelines. Perhaps more importantly, significant barriers to discharges are faced by facilities, healthcare
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3 staff, and families, including economic costs, traditional or cultural practices, and a lack of human and
4
5 physical resources. Within the context of improving the discharge process, teamwork and motivation
6
7 were identified by participants as critical facilitators required for change. The need for a standardized
8
9 national policy guiding pediatric discharges, implemented through education at pre-service and in-
10
11 service levels and coupled with appropriate community referral and follow-up, was broadly noted as
12
13 essential to improving outcomes for children.
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16
17 The discharge process occurs within the context of congested and overburdened facilities that are
18
19 competing for resources to triage, admit, treat, and discharge children. However, challenges to
20
21 providing optimal care are further compounded by traditional and cultural practices as well as the
22
23 socioeconomic status of the families of admitted children, which is consistent with previous research in
24
25 Uganda examining barriers to care for children.⁽⁷⁾ The predominant cultural idea that “traditional” and
26
27 “hospital” illnesses are mutually exclusive is often compounded with a generational conflict due to the
28
29 expectation of deferring to an elder’s advice.⁽⁷⁾ Financial barriers faced by families consist of
30
31 transportation costs, inpatient charges at private facilities, laboratory investigations, and medications
32
33 prescribed upon discharge, among others. These expenses are often difficult to manage, forcing families
34
35 to forego continued essential care following discharge. Furthermore, with males traditionally being the
36
37 decision-makers and managers of finances, inclusion of fathers in the medical care of their children may
38
39 be a critical component of strategies to address post-discharge morbidity and mortality.
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45 Clinical pathways or guidelines need to be both standardized and applicable to the reality of hospitals in
46
47 LMIC settings. In the Ugandan context, current discharge criteria are majorly based upon clinician
48
49 assessment and facility protocol which, when described, were largely inconsistent. The ongoing *Smart*
50
51 *Discharges* research program in Uganda provides a way to focus limited resources to children identified
52
53 to be the most vulnerable through risk-prediction modeling.⁽⁸⁾ Using this precision public health
54
55 approach,⁽⁹⁾ children identified during an admission can receive comprehensive discharge planning and
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3 guideline-based interventions.(8) The same research is also developing training programs to
4
5 complement policy and guidelines, with focused training for (1) community-level health workers, (2)
6
7 discharging facilities (i.e., hospitals), (3) receiving facilities (i.e., facilities that see children post-discharge
8
9 for follow-up) and (4) the caregivers themselves. Healthcare provider education as a key theme for
10
11 change was identified by participants across this study as instrumental to ensuring robust policy
12
13 development as well as integration of improved discharge practices into routine care.
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16
17 Patient care is often undertaken by both professionals and students; therefore, participants identified
18
19 the need for standardized, visible, and implementable guidelines to help facilitate holistic pediatric care.
20
21 One study analyzing the sustainability of implementing guidelines for pneumonia in LMICs found that
22
23 ever-changing staff played a negative role in the sustainability of interventions, emphasizing the need
24
25 for all levels of health professionals to be informed and well-versed in the protocols, with emphasis on
26
27 passing on the information to new healthcare workers in order to continue best practice.(10) An
28
29 important gap in current work is the need to affect discharge practices through improved policy and
30
31 guidelines at both national and hospital levels. Every focus group or individual interviewee spoke to the
32
33 importance of guidelines for practice. Improvement in this regard can thus provide the foundation for
34
35 positive change in the post-discharge care of children.
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41 Participants continually emphasized the importance of discharge planning for children throughout the
42
43 interviews, expressing unity and motivation to implement process changes. An Iranian study found that
44
45 a breakdown in communication between the healthcare team, patients, and families contributed to
46
47 parents' decisions to discharge their children against medical advice, a potential contributor to post-
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49 discharge mortality.(11) Empowering families, developing a trusting relationship with the healthcare
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51 team, and developing a plan for discharge at the time of admission were considered strategies towards
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53 improving health outcomes and compliance with medical care.(11)
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3 This qualitative exploratory study, designed to describe and provide a basis for further more conclusive
4 research, is subject to several limitations. First, this study was conducted across seven hospitals in
5 Uganda, both private not-for-profit and government. While this perspective added substantial
6 geographical and cultural balance, this study does not capture all regions, and thus may be biased
7 towards the regions and cultures in which the study was conducted. As well, there may be a lack of
8 transferability of findings to other countries or even other levels of health facilities. Second, a difficulty
9 in recruiting health care providers as evidenced by the, at times, small focus group sizes or inability to
10 reach hospital administration for an interview, was offset by the many focus groups and large regional
11 representation. Finally, this study may be subject to bias due to the fact that investigators conducting
12 the interviews and analysis have been involved in past post-discharge mortality research. Thus,
13 preconceived notions about barriers, facilitators, and ideas of change may have influenced the results.
14 However, this bias may also be beneficial in terms of connecting prior research findings to the
15 perspectives of the stakeholders being interviewed, thus ultimately benefiting the development of
16 effective solutions.
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36 Conclusion

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40 Understanding the burden of post-discharge mortality in LMICs through the context of the discharge
41 process has been a critical gap in the development of effective solutions to improve post-discharge
42 outcomes. The importance of post-discharge mortality is highlighted through the improved
43 understanding of current discharge practices and the exploration of barriers, facilitators, and solutions
44 from the perspective of Ugandan health professionals. The current discharge procedures are largely
45 based on hospital-specific protocol or clinician opinion, and not standardized guidelines. Barriers to
46 discharge are faced by facilities, healthcare staff, and families, and include economic costs, traditional or
47 cultural practices, and a lack of human and physical resources. Teamwork and motivation were
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3 identified as critical facilitators required for change. We identified a need for a standardized national
4
5 policy coupled with appropriate community referral and follow-up and education as essential to
6
7 improving outcomes for children. This work can serve to facilitate the development of sustainable and
8
9 effective interventions to improve post-discharge outcomes in Uganda and other similar LMIC settings.
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13 List of Abbreviations

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18 FG: Focus Group

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21 LMIC: Low-and middle-income country
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24 Consent for publication

25
26
27 Consent was obtained from participants for publication of data in signed consent forms.
28
29

30 Availability of data and material

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33
34 The datasets analysed during the current study are available from the corresponding author on
35
36 reasonable request. A sample of the data generated or analysed during this study are included in this
37
38 published article [and its supplementary information files]. Some datasets generated and/or analysed
39
40 during the current study are not publicly available due to participant confidentiality but are available
41
42 from the corresponding author on reasonable request.
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46 Authors' contributions

47
48
49 **Brooklyn Nemetchek, MN** – carried out data analysis and interpretation, drafted the initial manuscript,
50
51 critically reviewed and revised the manuscript, approved the final manuscript as submitted, and agrees
52
53 to be accountable for all aspects of the work.
54
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2
3 **Asif Khowaja, PhD** – contributed to data analysis, interpretation, and drafting of initial manuscript,
4
5 critically reviewed and revised the manuscript, approved the final manuscript as submitted, and agrees
6
7 to be accountable for all aspects of the work.
8
9

10 **Anthony Kavuma, MBChB, MPH** – carried out data acquisition, contributed to data interpretation,
11
12 critically reviewed and revised the manuscript, approved the final manuscript as submitted, and agrees
13
14 to be accountable for all aspects of the work.
15
16

17 **Olive Kabajaasi** – carried out data acquisition, contributed to data interpretation, critically reviewed and
18
19 revised the manuscript, approved the final manuscript as submitted, and agrees to be accountable for
20
21 all aspects of the work.
22
23

24 **Alex Owili, BSN** – contributed to study design and data interpretation, critically reviewed and revised
25
26 the manuscript, approved the final manuscript as submitted, and agrees to be accountable for all
27
28 aspects of the work.
29
30

31 **Mark Ansermino, MBBCh, MMed** – contributed to data interpretation, critically reviewed and revised
32
33 the manuscript, approved the final manuscript as submitted, and agrees to be accountable for all
34
35 aspects of the work.
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37

38 **Susan Fowler-Kerry, PhD** – contributed to data interpretation, critically reviewed and revised the
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40 manuscript, approved the final manuscript as submitted, and agrees to be accountable for all aspects of
41
42 the work.
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44

45 **Shevin Jacob, MD, MPH** – contributed to data interpretation, critically reviewed and revised the
46
47 manuscript, approved the final manuscript as submitted, and agrees to be accountable for all aspects of
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49 the work.
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2
3 **Nathan Kenya-Mugisha, MBChB, MMed** – contributed to study design and data interpretation, critically
4 reviewed and revised the manuscript, approved the final manuscript as submitted, and agrees to be
5 accountable for all aspects of the work.
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7

8
9
10 **Jerome Kabakyenga, MBChB, MMed**—contributed to study design and data interpretation, critically
11 reviewed and revised the manuscript, approved the final manuscript as submitted, and agrees to be
12 accountable for all aspects of the work.
13
14

15
16
17 **Matthew O. Wiens, Pharm D, PhD** – contributed to study conceptualization and design, coordinated
18 and supervised the project, contributed to data interpretation and drafting of initial manuscript,
19 critically reviewed and revised the manuscript and approved the final manuscript as submitted, and
20 agrees to be accountable for all aspects of the work.
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28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 Additional Files

48 49 Additional file 1

50
51 File format: Microsoft Word document (.docx)

52
53
54 Title: Appendix A

1
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3 Description: Nursing focus group interview guide, clinician focus group interview guide, and
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5 administration individual interview guide.
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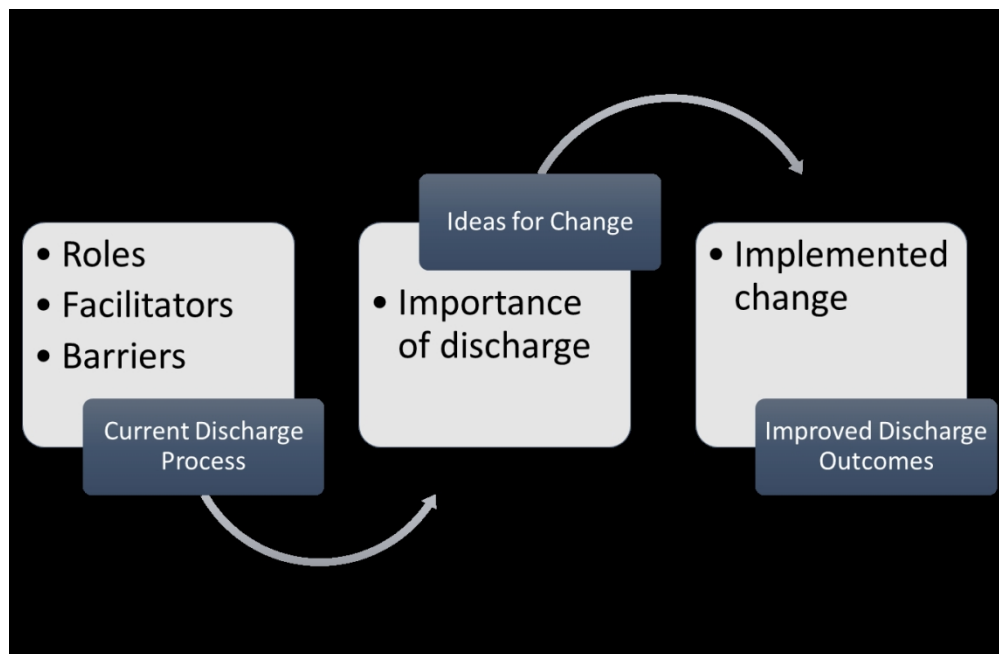


Figure 1

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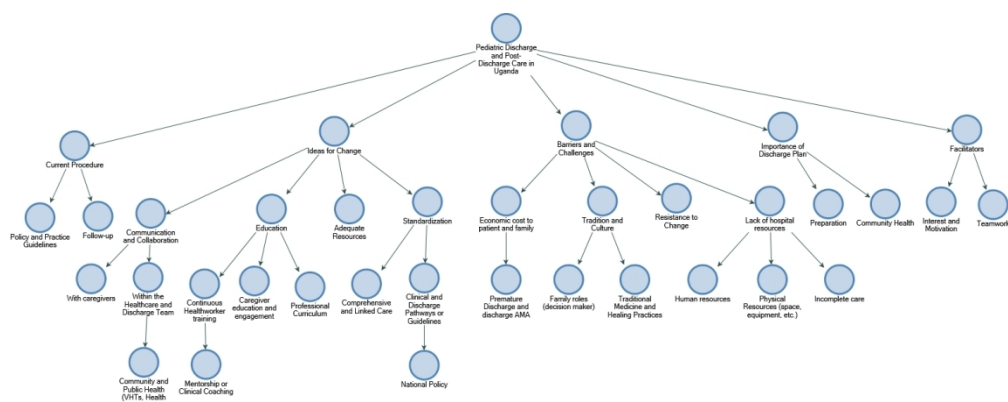


Figure 2

414x164mm (96 x 96 DPI)

Nurse Focus Groups

Interview Date:

Participant Code:

Participant demographics:

Age group: *Please indicate sex below your age range*

Age group	18-25	26-33	34-41	42-49	≥ 50
Sex: M/F					

Education attainment: *Please indicate work history below your profession category*

Profession/discipline	Certificate	Diploma	Undergraduate	Masters	Others
Total years in practice					
Duration of practice in the current hospital					

Discharge process focus group guide

- 1) How do you begin your day in the hospital ward?
 - a) Priority list, handover reports, chart review, review of discharges, and patient follow-up.
- 2) Walk me through the actual process of discharging a child treated for infections from your ward? (Pay attention to when the discharge process is initiated and by whom, planning discharge, teams involved, communication, actual discharge, and follow-up)
 - a) Can you describe to me a little more about the things (special/priorities) that you pay attention to, when effecting discharge?
 - b) Can you explain to me the factors that influence these considerations?
 - c) Are there any follow-up strategies for children discharged? If any, how its done, how often, and by who?
- 3) How long does the discharge process for a child treated for infections take?
 - a) Is the time uniform for every child? Clarify to us what determines the variation?
- 4) Can you describe the roles you assume/play during discharge?
 - a) Explain your role in assessment for readiness of the child for discharge? Describe what happens if you or the mother/caregiver doesn't think the child is well enough to go home? If the doctor says "go discharge that child", can you choose to wait another day due to your judgement? If possible can you give me a scenario?
- 5) Why do you think discharge planning is important? If any,
- 6) Describe to us the challenges you encounter when implementing discharges?
 - a) How have these challenges affected the discharge process?
 - b) Explain to us what you think can be done to improve this?
- 7) Describe the best way to organize a discharge team within this hospital?
- 8) In your opinion, describe the challenges you think about, if your hospital were to introduce a new discharge protocol? Explain what makes it easier for you when there is a new protocol?
- 9) If you were in charge, how would you develop a discharge plan for paediatric inpatients in this hospital?

Physician/Clinical Officer Focus Groups

Interview Date:

Participant Code:

Participant demographics

Age group: *Please indicate sex below your age range*

Age group	18-25	26-33	34-41	42-49	≥50
Sex M/F					

Education attainment: *Please indicate work history below your profession category*

Profession/discipline	Intern	MBChB	MMED	MSc/MPH	PhD
Total years in practice					
Duration (months of practice in the current hospital)					

Focus group discussion guide

- 1) How do you begin your day in the hospital ward?
 - a) Priority list, handover reports, chart review, review of discharges, and patient follow-up.
- 2) Describe to us what processes you consider when discharging a child treated for sepsis?(Pay attention to when the discharge process is initiated and by whom? Planning discharge, teams involved, communication, discharge, and follow-up)
 - a) When does the discharge process begin?
 - b) Explain the priorities you consider when thinking of discharge a child treated for sepsis?
 - c) Follow-up strategies? How it's done, how often, and by who?
- 3) Describe to us the challenges that you face when considering discharge?
 - a) How do you think these challenges affected the children you discharge from the hospital?
 - b) Describe what you think can be done to improve this process?
- 4) Can you describe what roles you assume/play during the discharge process?
 - a) Can you describe to me a little more about how your current roles/activities in the process of discharge have been helpful to your patients?
 - b) Is the decision to discharge a child, solely made by you-the Doctor? Describe what happens if a member of the team on the ward or the mother/caregiver doesn't think the child is well enough to go home?
 - c) Can you explain to us what you think was not right?
 - d) Describe to us the changes you would like to see in the current discharge process?
- 5) Describe to us the best way to organize a discharge team at this hospital?
- 6) How do you see a discharge team function in the hospital setting?
- 7) In your opinion, explain the challenges or facilitators you think about, if your hospital were to introduce a new paediatric discharge protocol?
- 8) If you were in charge, how would you develop a discharge plan for paediatric inpatients in this hospital?

Hospital Administrator In-depth Interviews

Interview Date:

Participant Code:

Participant demographics

Age group: *Please indicate sex below your age range*

Age group	18-25	26-33	34-41	42-49	≥50
Sex M/F					

Education attainment: *Please indicate work history below your profession category*

Profession/Discipline	Undergraduate	MBChB	MMED	MSc/MPH	PhD
Years as administrator					
Years in current position					

In-depth interview guide

- 1) Describe some of the existing policies/guidelines regarding discharge practices in the paediatric unit, for children treated for infections.
- 2) Explain the things regarding discharge guidelines for children treated for infections, that you would like to see being implemented and are not currently in place?
 - a) What are some of the reasons why you want to see them?
- 3) What are some of the reasons to why they are not being done? (Pay attention to human resources, financing strategy, policies)
- 4) Why do you think it is important to plan discharges for children treated for sepsis?
- 5) Describe what you think is required to implement a paediatric discharge protocol in your hospital?
- 6) Describe the current strengths of your hospital in implementing the discharge process?
- 7) Describe the changes in the current discharge practices you assume need to be made to implement a new paediatric discharge protocol?
- 8) Describe the probable challenges you foresee with implementing a new paediatric discharge protocol?
- 9) How can these challenges be addressed?
- 10) If you were in charge, how would you develop a discharge plan for paediatric inpatients in this hospital?

Standards for Reporting Qualitative Research (SRQR)

O'Brien B.C., Harris, I.B., Beckman, T.J., Reed, D.A., & Cook, D.A. (2014). Standards for reporting qualitative research: a synthesis of recommendations. *Academic Medicine*, 89(9), 1245-1251.

No.	Topic	Item	Page no.
Title and abstract			
S1	Title	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes objective, methods, results, and conclusions	1
Introduction			
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	4
S4	Purpose or research question	Purpose of the study and specific objectives or questions	4
Methods			
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., positivist, constructivist/interpretivist) is also recommended	5
S6	Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, or transferability	n/a
S7	Context	Setting/site and salient contextual factors; rationale ^a	5
S8	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale ^a	6
S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	6,7
S10	Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale ^a	6

S11	Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	6 (reference to additional file)
S12	Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	7,8,9
S13	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	7
S14	Data analysis	Process by which inferences, themes, etc., were identified and developed, including researchers involved in data analysis; usually references a specific paradigm or approach; rationale ^a	7 (with reference to figure 1 and 2)
S15	Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale ^a	7
Results/Findings			
S16	Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	9-18
S17	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	9-18
Discussion			
S18	Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	18-20
S19	Limitations	Trustworthiness and limitations of findings	20, 21
Other			
S20	Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	3
S21	Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting	3

^aThe rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

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Exploring Healthcare Providers' Perspectives of the Pediatric Discharge Process in Uganda: A Qualitative Exploratory Study

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Exploring Healthcare Providers' Perspectives of the Pediatric Discharge Process in Uganda: A Qualitative Exploratory Study

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42 **Keywords:**

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44 Pediatrics, Patient Discharge, Qualitative Research, Uganda

Abstract

The burden of childhood mortality continues to be born largely by low-and middle-income countries.

The critical post-discharge period has been largely neglected despite evidence that mortality rates during this period can exceed inpatient mortality rates. However, there is a paucity of data on the pediatric discharge process from the perspective of the healthcare provider. Provider perspectives may be important in the development of an improved understanding of the barriers and facilitators to improving the transition from hospital to home.

Objectives

To explore healthcare providers' and facility administrators' perspectives of the pediatric discharge process with respect to: (1) current procedures, 2) barriers and challenges, 3) ideas for change, 4) facilitators for change and 5) the importance of discharge planning.

Design

A qualitative exploratory approach using focus groups (14) and in-depth interviews (7).

Setting

This study was conducted at seven hospitals providing pediatric care in Uganda.

Results

Current discharge procedures are largely based on hospital-specific protocols or clinician opinion, as opposed to national guidelines. Some key barriers to an improved discharge process included caregiver resources and education, critical communication gaps, traditional practices, and a lack of human and physical resources. Teamwork and motivation to see improved pediatric transitions to home were

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2
3 identified as facilitators to implementing the ideas for change proposed by participants. The need for a
4
5 standardized national policy guiding pediatric discharges, implemented through education at many
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7 levels and coupled with appropriate community referral and follow-up, was broadly perceived as
8
9 essential to improving outcomes for children.
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12 13 Conclusions

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16 Although significant challenges and gaps were identified within the current health system, participants'
17
18 ideas and the identified facilitators provide a significant basis from which change may occur. This work
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20 can facilitate the development of sustainable and effective interventions to improve post-discharge
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22 outcomes in Uganda and other similar settings.
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Strengths and Limitations of this Study (up to 5 bullet points)

- This study represented four regions in Uganda and included both private and public facilities
- This study may have limited generalizability to other countries, particularly those outside of sub-Saharan Africa
- Although some focus groups were at times small, the high degree of interest and participation provided deep insights into barriers faced by facilities, health workers and caregivers
- The lack of the caregiver perspective limits some of the conclusions of these data
- The information gathered through these qualitative interviews can provide critical information in designing effective interventions to improve the pediatric discharge process

Funding Statement

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Competing interests

The authors declare that they have no competing interests

Table Legend

Table 1: Hospital Demographics

Table 2: Participant Demographics

Background

The third of 17 Sustainable Development Goals commit the world to “ensure healthy lives and promote well-being for all at all ages” by the year 2030, a key aspect of which is decreasing under-five mortality.(1) However, the burden of under-five mortality continues to be born largely by low-and middle-income countries (LMICs), with half of the world’s total under-five deaths occurring in Sub-Saharan Africa alone.(2) Over the past several decades, significant effort has been made to address the diagnosis and treatment provided during acute care, but care following hospital discharge has been largely neglected in research, policy, and practice.(3) A recent systematic review found that in LMICs, post-discharge deaths often times exceed the in-hospital mortality rate. Furthermore, most post-discharge deaths occur at home, suggesting that the point of discharge represents an important opportunity for innovation to improve health outcomes among children. Within the Ugandan context, a recent study found that 5% of under-five children who had been hospitalized for infectious illness died in the six months following discharge, often at home.(4)

Evidence from a recent proof-of-concept study in Uganda, known as *Smart Discharges*, demonstrated improved outcomes following discharge through an educational intervention and community-level referrals for follow-up.(5) Discharge education and follow-up after discharge appear to be critical components necessary to improve the long-term survival of children admitted with serious infectious illness.(5) However, little is known regarding the facilitators and barriers to adoption within the Ugandan health system. Understanding the current discharge processes in Ugandan hospitals and the challenges they face is a necessary step prior to further adoption and scaling-up of such processes. Therefore, within the context of severe pediatric infectious illness, this study aimed to explore healthcare providers’ and facility administrators’ perspectives of the discharge process, with respect to: 1) current

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3 procedures, 2) barriers and challenges, 3) ideas for change, 4) facilitators for change and 5) the
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5 importance of discharge planning.
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8 9 Methods

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17 A qualitative exploratory study was conducted and the data was prospectively collected through focus
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19 groups (FGs) and in-depth interviews with key professional stakeholders in order to explore the current
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21 pediatric discharge process within the Ugandan health care system, an area that has yet to be
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23 extensively studied. This study design is ideal for understanding and describing the gap in this area of
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25 research, creating a basis upon which further research may build.
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29 30 Patient and Public Involvement

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33 Patients and public were not involved in the development of the research question or outcomes.
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36 37 Study Setting

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40 The study was conducted at seven sites across Uganda, including five public, government-funded
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42 hospitals, and two private not-for-profit hospitals. Government-funded hospitals included: Lira Regional
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44 Referral Hospital (LRRH), Gulu Regional Referral Hospital (GRRH), Jinja Regional Referral Hospital (JRRH),
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46 Masaka Regional Referral Hospital (MRRH-Masaka), and Mbarara Regional Referral Hospital (MRRH-
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48 Mbarara). Private not-for-profit hospitals included Holy Innocents Children's Hospital (HICH) in Mbarara
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50 and Kisiizi Hospital in Rukungiri district. The hospitals represent the regional distribution of major
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hospitals across Uganda. Hospitals varied with regard to bed capacity, number of annual pediatric admissions, and numbers of staff (**Table 1**).

Table 1: Hospital Demographics

Hospital site	Approximate total bed capacity	Number of Pediatric Beds	Number of Children age 0-5 years admitted annually*	Pediatric Physicians	Pediatric Nurses
GRRH, Gulu	397	32	5,774	9	31
JRRH, Jinja	408	50	7,559	8	17
MRRH, Masaka	330	45	4,876	7	7
MRRH, Mbarara	600	79	2,398	17**	17
HICH, Mbarara	60	60	5,623	5	21
Kisiizi hospital, Rukungiri	250	38	1,326	5	11
LRRH, Lira	346	70	3,428	4	20

*Average of total admissions aged 0-60 months for the three years: 2015, 2016, 2017

**Includes 9 Senior House Officers (Masters of Pediatric Medicine students who attend to patients as part of their training requirement but are not employees of Mbarara Regional Referral hospital)

Sampling and Inclusion Criteria for Focus Groups and In-Depth Interviews

Site participants were recruited using purposive sampling. Frontline pediatric providers (i.e., nurses and doctors) who had worked in the pediatric ward for at least two months preceding the time of data collection were eligible FG participants. Hospital administrators were considered eligible for participation in the in-depth interviews if they were currently involved in clinical administrative work and had some degree of oversight for the pediatric ward. Initial contact with all eligible study participants was through each respective hospital's human resources department.

Data Collection

Interviews and FGs were conducted between April to July 2018. Fourteen FG discussions—seven with nurses and seven with physicians/clinical officers—were conducted across the seven study sites, together with seven in-depth interviews with hospital administrators from six study sites. The hospital administrator at one study site was unavailable during the interviewing period and was thus excluded. No other participants dropped out. Each FG consisted of 3-5 participants. Nursing FGs lasted approximately 35-75 minutes, clinician FGs approximately 50-80 minutes, and in-depth semi-structured interviews approximately 15-50 minutes. All interviews and FGs were audio recorded following participant permission. FGs and in-depth interviews were conducted by a trained research assistant (AKA or OK) using pilot-tested semi-structured interview guides consistently applied across interviews (**Additional file 1**). The two Ugandan interviewers, one male and one female, were hired for this specific project and had no previous involvement in *Smart Discharges* research or personal relationship to the study participants. Repeat interviews, and participant data checking were not conducted.

Ethics

Ethical approval was obtained from the research ethics boards at the University of British Columbia (H18-00403) and Mbarara University of Science and Technology (MUREC 1/7). All focus groups and in-depth interviews were conducted in a private hospital meeting room after obtaining written informed consent from participants. Participants were provided with an honorarium of 25,000 Ugandan Shillings (approximately \$7 USD).

Analysis

Focus groups and in-depth interviews were recorded and transcribed verbatim by two interviewers (AKa and OK) and then spot-checked for consistency by another member of the investigative team (BN).

Transcripts were analyzed using NVivo 11 software (QST International, Cambridge, MA). Mind-mapping, coding, and node structures were identified and reviewed by two team members (BN, AKh). Coding of the data aimed to identify categories and linkages and to explore patterns. Relationships between five a-priori themes are depicted using a conceptual framework (**Error! Reference source not found.**), from which further sub-themes emerged (**Figure 2**) in an effort to better understand the pediatric discharge process. The standards for reporting qualitative research (SRQR) criteria was utilized in reporting findings.⁽⁶⁾

Figure 1: Conceptual Framework

Figure 2: Discharge Theme Map

Results

A total of 58 participants, with wide ranges of experience and training, contributed to the 14 FGs and seven in-depth interviews (**Table 2**). Nursing FGs included 28 nurses holding either certificates or diplomas. Nurses had, on average, more practical experience in months ($M=116.7$, $SD= 90.7$) compared to that for all participants ($M=37.1$, $SD= 82.9$). Clinician FGs included 23 clinicians/interns with significantly less practice experience than their nursing counterparts ($M= 24.1$, $SD= 38.2$). Six of the seven hospital administrators held a Masters of Medicine, with most having between 2 and 8 years of administrative experience ($M=6.7$, $SD=11.3$).

Table 2: Participant Demographics

Hospital	Healthcare Worker	Number of Participants	Gender (% female)	Age Group	Education
GRRH, Gulu	Nursing	4	100%	1 (25-33) 1 (34-41) 2 (42-49)	1 (certificate) 3 (diploma)
	Clinician	4	25%	1 (18-25) 2 (26-33) 1 (42-49)	3 (intern) 1 (MBChB)
	Administration	1	100%	(42-49)	MMed
JRRH, Jinja	Nursing	5	100%	3 (26-33) 2 (34-41)	2 (certificate) 3 (diploma)
	Clinician	4	0%	2 (26-33) 2 (34-41)	4 (intern)
	Administration	2	50%	2 (42-49)	1 (diploma) 1 (MMed)
MRRH, Masaka	Nursing	3	100%	1 (26-33) 1 (34-41) 1 (42-49)	1 (certificate) 2 (diploma)
	Clinician	3	0%	1 (18-24) 1 (26-33) 1 (34-41)	3 (intern)
	Administration	1	0%	(42-49)	MMed
MRRH, Mbarara	Nursing	4	100%	2 (18-25) 1 (26-33) 1 (42-49)	3 (certificate) 1 (diploma)
	Clinician	4	75%	3 (26-33) 1 (34-41)	4 (MBChB)
	Administration	1	0%	(34-41)	MMed
HICH, Mbarara	Nursing	4	75%	1 (18-25) 3 (26-33)	2 (certificate) 2 (diploma)
	Clinician	3	33%	3 (26-33)	3 (MBChB)

	Administration	1	0%	(34-41)	MMed
Kisiizi Hospital, Rukungiri	Nursing	3	66%	1 (18-25) 1 (26-33) 1 (34-41)	1 (certificate) 2 (diploma)
	Clinician	2	0%	1 (26-33) 1 (34-41)	2 (intern)
	Administration	1	0%	>50	MMed
LRRH, Lira	Nursing	5	100%	2 (26-33) 1 (34-41) 2 (42-49)	5 (diploma)
	Clinician	3	33%	3 (26-33)	2 (intern) 1 (MBChB)
	Administration	-	-	-	-

Key themes

Five a-priori themes became the framework for initial analysis, from which sub-themes and concepts emerged, expanding the coding scheme to bring further clarity and understanding to the pediatric discharge process (**Figure 2**).

Current Procedures

Participants described typical daily activities in the pediatric wards, including ward rounds, seeing outpatients, admitting, treating, and discharging children. Participants generally stated that they were unaware of written guidelines or policies regarding discharge processes for children admitted with infectious illnesses. Although the Uganda Clinical Guidelines 2016(7) were occasionally mentioned, participants largely cited either hospital-specific Standard Operating Procedures (SOPs) for specific disease processes, implied institutional policy, or departmental culture as the basis for current discharge

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3 practices. As one administrator stated, “I think really they [standards/guidelines] are implied, they are
4 not explicit that they are written down, and that’s where the gaps are” (Admin 5). These implied criteria
5 are based on assessed clinical improvement. Health professionals in the FGs noted that mothers with
6 more schooling had greater understanding of the importance of follow-up for their child.
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12 Current pediatric post-discharge follow-up procedures were described, with one administrator noting
13 the only community-level, post-discharge follow-up that occurred was that undertaken by research
14 studies. Clinicians at one of the private hospitals stated that one nurse traveled each Saturday to
15 different regions in the hospital’s catchment area to visit malnourished children recently discharged;
16 however, all other children were given a follow-up date at the discharging hospitals outpatient clinic.
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19 Participants consistently identified follow-up clinics for specific chronic diseases such as HIV,
20 tuberculosis (TB), malnutrition, sickle cell, and cardiac conditions. Referral to these chronic diseases-
21 specific clinics are common and often stated to be part of guidelines; however, patients admitted for
22 acute infectious illness are given a post-discharge review date dependent upon clinician judgement
23 determined on an individual basis and highly reliant upon the many compounding factors (such as
24 severity of illness, condition at discharge, etc.) involved in the child’s illness. Most participants stated
25 they did not give review dates to all children with infectious illnesses, and review dates, when given,
26 were scheduled in an outpatient clinic (usually the discharging facility) at two to three weeks post-
27 discharge.
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44 Barriers/Challenges

45 *Barrier: Socioeconomic Cost to Patients and Families*

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52 Socioeconomic issues such as finances and transportation play a significant role in all aspects of health
53 and health seeking, not only for discharge and follow-up care, but also in timely initial treatment,
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3 readmission, or referral to a higher level of care. Clinicians talked of caregivers reaching the hospital
4 with a child too sick to save: *“They will tell you they have taken like three days because they were*
5 *looking for money to meet their transport costs”* (Clinician 23). Private hospital employees cited
6 challenges related to bills incurred. Parents desperate for care bring a child to a private hospital, but,
7 upon discharge, they are unable to pay their bill or decide to forego any post-discharge treatment due
8 to finances.
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11 Both private and public hospitals frequently talked about discharging children prematurely or against
12 medical advice, often due to the caregiver’s request. This decision was largely related to the financial
13 burden that families experience in caring for their hospitalized child or due to the need to care for other
14 children at home. *“Sometimes you want to keep the patient for a longer time but they are unable, they*
15 *are unwilling to stay. So... you make a decision that is not called for and you discharge them*
16 *prematurely”* (Clinician 1).
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19 The financial state of the family is also influential when a clinician recommends medication to be taken
20 at home or that a child be followed-up after discharge. Regional Referral Hospitals (RRHs) in Uganda are
21 few and yet serve large catchment areas, both in terms of geography and population, making follow-up
22 at this level of facility very difficult for patients and facilities. It is common practice to send a child home
23 with oral antibiotics; however, medications are often not free and thus are sometimes not purchased,
24 leaving children vulnerable to subsequent deterioration or recurrence of infection. Whether families
25 purchase these medications is not known unless they attend a follow-up appointment or are readmitted
26 to hospital. *“There are really mothers even if Ampiclox [antibiotic] is two thousand [Ugandan Shillings;*
27 *about \$0.50 USD], they will not buy it; they don't have the money”* (Clinician 21). One administrator talks
28 of the many interwoven socioeconomic barriers to complete care for the child, saying: *“there are always*
29 *issues of resources and transport... if the health facility that you want the child to be seen at is far away,*
30 *then they are unlikely to go there because mostly the people we treat are very poor so they can't afford*
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3 *to come back or to buy the medicines or even to buy the basic things like soap for hand washing. Or they*
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5 *don't have access to clean water" (Admin 7).*
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8 *Barrier: Tradition and Culture*

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11 Traditional and cultural practices and family roles are important aspects of health, including a child's
12 discharge and follow-up. Although a mother may wish for her child to remain admitted, purchase
13 medications, or attend a follow-up appointment, pressure from the father or male decision-maker may
14 limit her ability to complete all necessary aspects of care. Fathers often hold the finances, thus directly
15 affecting whether the mother can complete a follow-up appointment or obtain medications upon
16 discharge. Elders (such as the mother-in-law of the mother) also influence health-seeking behaviour and
17 may lead a caregiver to either forego formal medical care or supplement with traditional healing
18 practices, which may itself hinder a child's recovery or even precipitate further illness. Traditional
19 healers at times conduct non-sterile surgical procedures, precipitating further illness and infection.
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21 *"...they have this pressure at home and they are like no this condition will not be treated by those*
22 *medications; if we did these cuts to the child's body, they will help... like there are those cases we receive*
23 *here; the child has been having diarrhoea, he is dehydrated, he is not feeding. So this, in the community*
24 *there, will be interpreted as the child having 'ebiino' [false teeth]- that is why the child is not*
25 *breastfeeding. Yet you as a clinician, you know that this child is dehydrated and this is why the child has*
26 *failed to breastfeed" (Clinician 1). Sometimes when health workers discharge a child prematurely, they*
27 *knew that it was because the family wanted to try cultural healing practices: "these common cases of*
28 *upper respiratory tract infections, from the hospital, they [go] for local tonsillectomy. One, two, three*
29 *days the child is back with severe anaemia, septicaemia, very sick" (Clinician 23).*
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Barrier: Lack of Hospital Resources

The issue of human resources largely equates to workload and the understaffing that is prevalent in Ugandan medical facilities. Participants talk of a nurse working alone in a ward, how she cannot do all of the procedures, administer medications, and provide thorough teaching, and so, she will end up prioritizing emergencies and each interaction may have lesser quality than she would have liked to provide. Clinicians see large numbers of children each day and may, therefore, either prioritize cases or allocate tasks to students. Many of the RRHs are teaching hospitals. One hospital stated that due to inadequate staffing, medical interns and Senior House Officers (SHOs) in pediatrics usually ran the pediatric ward. Busy hospitals mean that the most experienced are managing the emergencies, leaving junior clinicians or students- those least experienced- to run the wards and manage discharges.

Issues of inadequate physical resources include shortages of supplies and medications, lack of investigatory capacity, lack of sufficient beds or hospital space, among other physical constraints present in Ugandan pediatric wards. Participants from many hospitals stated that their hospital laboratory analyzer for measuring complete blood counts was out of commission, meaning that even simple investigations often used to guide treatment and assess readiness for discharge had to be done from generally unaffordable private laboratory facilities: *“At discharge, most of the diagnosis we make here, we do them clinically because of lack of investigations. So, we usually discharge patients when we don't know the real focus. And at times because we are just treating generally we might not have really tackled the focus of the septicaemia and the children usually come back”* (Clinician 16). Hospital bed capacity also affects not only inpatient care, but also a child's discharge, as clinicians at times are forced to discharge prematurely due to space constraints. It is common to see one bed with up to four pediatric patients, each with differing conditions, *“...this one maybe has measles which has not shown up, this one*

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3 *has acute watery diarrhoea, then this one has... you know, we are just infecting and not helping the*
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5 *children” (Clinician 10).*
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8 Ideas for Change 9

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12 Administrators, clinicians, and nurses brought forward ideas for change largely in relation to the many
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14 barriers and challenges they had identified.
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16 *Idea: Adequate Resources* 17

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21 Participants spoke to the need for adequate human and physical resources which would improve their
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23 ability to investigate, diagnose, treat, and discharge children admitted for infectious illness. It was
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25 acknowledged that families often do not purchase items such as discharge medications that are not
26
27 provided outside of the public system due to their socioeconomic status. Therefore, the common
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29 perception was that public, government-funded facilities should be equipped with the necessary
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31 supplies to treat a child and provide medications required upon discharge in order to ensure a full
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33 recovery. Further resources not currently in place in many facilities were suggested as potentially
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35 beneficial, such as including a social worker as part of the discharge team and a ward telephone to be
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37 used for follow-up.
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40 *Ideas: Standardization* 41

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45 Comprehensive, linked care was deemed necessary to improve current practices. A key aspect of
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47 comprehensive care is strengthening the Ugandan referral system, which was stated to not function
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49 optimally in its current state. Many participants envisioned a system in which, upon discharge, children
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51 could be connected to their local health centre or district hospital where they could be followed-up and
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53 referred back up to the RRHs if required. Referral both up and down the chain was identified to be a
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2
3 current difficulty in the system. *“Continuity of care from the hospital to the community; I think that is the*
4 *best way we can help these children of ours grow very well”* (Clinician 8). In-hospital care should not
5
6 stand alone, but be integrated within a larger vision; according to participants, a holistic approach is key
7
8 for lasting change and improved outcomes after discharge, including aspects of preventive and
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10 community measures such as immunization, sanitation, clean water, education, transport, and road
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12 improvement.
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17 Clinical pathways/guidelines for discharge, at both national and hospital levels, was considered of great
18
19 importance to every health provider interviewed. National policy from the Ugandan Ministry of Health
20
21 and other governing bodies influence what occurs in the medical system. Clinicians stated that having a
22
23 well-designed, endorsed, national policy for discharge for RRHs would be essential to ensure uptake and
24
25 standardization both within and between care facilities. However, change requires political will, so *“... if*
26
27 *we don’t have a lot of buy-in or commitment from the Ministry of Health and support for them because*
28
29 *we need resources, then it becomes difficult to expect facilities to implement it”* (Admin 7).
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33 It was emphasized that clinical pathways or guidelines implemented at the national level should be
34
35 applicable to the realities observed at the hospital level, taking into consideration resource availability.
36
37 Participants often talked of the importance of a pre-structured discharge form, wherein the discharging
38
39 clinician could easily fill in all required information to provide a holistic view of the child’s health status
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41 along with the comprehensive plan for discharge and follow-up. With such a standardized discharge
42
43 pathway, the discharging clinician can better facilitate communication with families, the healthcare
44
45 team, and communities. One clinician identified the possibility of a “discharge secretary”, whose job
46
47 would be to ensure that discharge forms are filled out in their entirety, complete with a clinician
48
49 signature, to aid accountability that appropriate follow-up is made with lower-level health facilities and
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51 to ensure that a copy of the discharge form is retained for future reference and follow-up.
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3 *Idea: Education*
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7 The healthcare team bears the important role of health education: *"...to see that they will not come back*
8 *in the same situation again. Should it happen again, they will go for healthcare faster than they came*
9 *this time around. And if it happens to another child, they should be able to identify that this one is this,*
10 *and it doesn't need local herbs or anything, it needs to go to the hospital"* (Clinician 3). One
11 administrator from a private hospital spoke of their hospitals move towards providing a discharge
12 summary in the local language to facilitate communication and reinforce the education provided by
13 health professionals. Going from individual caregiver education to the broader community level, one
14 clinician suggested that a small compulsory course on antenatal and child health be integrated into the
15 national education system: *"Because every woman is a potential mother even a father. So, to know*
16 *certain basic, basic things, it will educate the whole nation"* (Clinician 3).
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30 A common theme among participants was that continuous health worker training is required not only
31 for those working in hospitals, but also those working at lower level facilities and within communities, to
32 ensure all parties are informed. Whatever protocol or guideline is put into place, they must be both
33 accessible in real-time and paired with appropriate training to ensure their relevance and applicability
34 are optimally conveyed to the end-user: *"if you make the clinicians understand the contents of that*
35 *template, it can also increase its acceptability and its being put to use"* (Clinician 20). Once a change to a
36 standardized discharge protocol is developed and implemented, clinicians and administrators spoke of
37 the need to also include it into pre-service training (i.e., medical and nursing curricula).
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48 Health worker education includes equipping and empowering professionals working in lower-level
49 facilities and communities to be able to receive discharged children in follow-up (down referrals), to
50 manage simple cases, and in so doing, take some of the burden off of RRHs. *"I would want to be able to*
51 *train and coach and mentor the health workers at the lower level to be able to carry some of this"*
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3 (Admin 2). At the local level, Village Health Teams (VHTs) are members of each community who may be
4
5 trained and then utilized in follow-up for children recently discharged, assisting the caregiver with
6
7 identifying signs of further illness and reminding of the importance of follow-up appointments.
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10 *Idea: Communication and Collaboration*

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14 Caregivers are important members of the healthcare team; they are constantly with the child and are
15
16 often utilized by health professionals as a source of history, presenting illness, and treatment
17
18 progression. *“There is this saying that the mother is the best doctor because she spends most of the time*
19
20 *with her child”* (Clinician 22). The mother or caregiver ought to participate in determining the child’s
21
22 readiness for discharge as she is ultimately the one who will continue to care for the child upon
23
24 discharge. Communicating well with the caregiver from the beginning—from admission—may facilitate
25
26 an open and understanding relationship between the family and medical team and ensure that
27
28 caregivers are fully informed. A discharge form given to the caregiver outlining the inpatient treatment
29
30 and discharge instructions is common practice in Ugandan hospitals. The private hospitals both
31
32 mentioned a gradual transition to a computerized system which would include the retention of an
33
34 electronic copy of medical records, including the discharge form. This will aid in communication and
35
36 continuity of care for those patients who do not bring their discharge form for follow-up visits or
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38 readmissions.
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43 Discharge as a team activity requires collaboration and clear communication. Key players identified in
44
45 the discharge team included the caregivers, clinicians, nurses, administration, and other health
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47 professionals such as consultants, nutritionists, or physiotherapists involved in the care of the
48
49 hospitalized patient. Although participants spoke to the unlikely nature of being able to gather together
50
51 to discharge patients, this barrier was thought to be able to be mediated by strong communication
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53 within the team and fulfilling one’s professional role. Clinicians stated the value of nursing staff, noting
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3 that nurses have thoughtful insights gained through the time spent assessing patients throughout their
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5 shifts.
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8 Collaboration and communication at the community-level include inter-facility communication between
9
10 hospitals, lower-level health facilities and Village Health Teams (VHTs). Given that RRHs do not have the
11
12 capacity to follow up all discharged children, follow-up is an important community-level aspect of care.
13
14 Many participants thought that follow-up could be conducted by the health facility nearest the patient's
15
16 home or by the VHT. An added benefit to local follow-up is that these interactions are convenient times
17
18 to address broader public health issues affecting children, families and the communities at large, such as
19
20 immunization, hygiene, and other areas of health promotion and preventive medicine.
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24 Facilitators

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28 Participants overall noted an attitude of teamwork, motivation, and interest in the discharge and follow-
29
30 up process as an important aspect of a child's health journey. Participants consistently referred to
31
32 themselves as a team working towards the common, shared goal of healthier patients, communities,
33
34 and society. *"... my team, they are willing, they have that desire to make sure that their patients
35
36 survive... most of them go over and above what is their call to serve those children... So I know they don't
37
38 want them to go and die at home so the willingness to find a solution if they know somebody can do to
39
40 keep these children alive I know they would jump on it... the teams work with that passion to keep those
41
42 babies alive and grow to adulthood"* (Admin 2).
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47 Importance of Discharge Planning

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50 When asked about the importance of discharge planning, participants often spoke of preparation.
51
52 Discharge planning allows families and the healthcare team to prepare for a child to return to their
53
54 community. *"Its like preparation for this child to get back into the community... you can get to know how
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3 *to discharge this patient and how to help them when they get back into the community” (Nurse 22). A*
4
5 plan for discharge can allow the healthcare team to communicate early on with the family about a
6
7 pending discharge, allowing them time to coordinate issues such as transportation or purchasing any
8
9 medications required after discharge, thus ensuring the readiness of the family for the transition home.
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11 Discharge planning allows for a consistent understanding and continuous evaluation of readiness for
12
13 discharge, which may help reduce premature or uncoordinated discharges that lead to deaths or
14
15 frequent readmissions and associated healthcare costs to both families and government facilities. There
16
17 was a recognized need to carefully manage children through to the discharge and even afterward, which
18
19 may be aided by a discharge plan. Often times for hospital staff, once a child is discharged, how a child
20
21 progresses afterwards can be forgotten without something specifically guiding a process for care post-
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23 discharge.
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29 Discussion

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33 This study found that in Ugandan hospitals, current discharge procedures for children with infectious
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35 etiologies are largely based on hospital-specific protocol or clinician opinion, as opposed to universal
36
37 guidelines. Perhaps more importantly, significant barriers to discharges are faced by facilities, healthcare
38
39 staff, and families, including economic costs, traditional or cultural practices, and a lack of human and
40
41 physical resources. Within the context of improving the discharge process, teamwork and motivation
42
43 were identified by participants as critical facilitators required for change. The need for a standardized
44
45 national policy guiding pediatric discharges, implemented through education at pre-service and in-
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47 service levels and coupled with appropriate community referral and follow-up, was broadly noted as
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49 essential to improving outcomes for children.
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3 The discharge process occurs within the context of congested and overburdened facilities that are
4 competing for resources to triage, admit, treat, and discharge children. However, challenges to
5 providing optimal care are further compounded by traditional and cultural practices as well as the
6 socioeconomic status of the families of admitted children, which is consistent with previous research in
7 Uganda examining barriers to care for children.⁽⁸⁾ The predominant cultural idea that “traditional” and
8 “hospital” illnesses are mutually exclusive is often compounded with a generational conflict due to the
9 expectation of deferring to an elder’s advice.⁽⁸⁾ Financial barriers faced by families consist of
10 transportation costs, inpatient charges at private facilities, laboratory investigations, and medications
11 prescribed upon discharge, among others. These expenses are often difficult to manage, forcing families
12 to forego continued essential care following discharge. Furthermore, with males traditionally being the
13 decision-makers and managers of finances, inclusion of fathers in the medical care of their children may
14 be a critical component of strategies to address post-discharge morbidity and mortality.

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Clinical pathways or guidelines need to be both standardized and applicable to the reality of hospitals in
LMIC settings. In the Ugandan context, current discharge criteria are majorly based upon clinician
assessment and facility protocol which, when described, were largely inconsistent. The ongoing *Smart
Discharges* research program in Uganda provides a way to focus limited resources to children identified
to be the most vulnerable through risk-prediction modeling.⁽⁹⁾ Using this precision public health
approach,⁽¹⁰⁾ children identified during an admission can receive comprehensive discharge planning
and guideline-based interventions.⁽⁹⁾ The same research is also developing training programs to
complement policy and guidelines, with focused training for (1) community-level health workers, (2)
discharging facilities (i.e., hospitals), (3) receiving facilities (i.e., facilities that see children post-discharge
for follow-up) and (4) the caregivers themselves. Post-discharge follow-up for the most vulnerable
children is a key component of this program. Although this study utilized referral hospitals, which may
often be difficult for rural patients to access following discharge, this program leverages lower level

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3 facilities to conduct follow-up care through a unique “back-referral” program. Healthcare provider
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5 education as a key theme for change was identified by participants across this study as instrumental to
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7 ensuring robust policy development as well as integration of improved discharge practices into routine
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9 care.

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12 Patient care is often undertaken by both professionals and students; therefore, participants identified
13
14 the need for standardized, visible, and implementable guidelines to help facilitate holistic pediatric care.

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16 One study analyzing the sustainability of implementing guidelines for pneumonia in LMICs found that
17
18 ever-changing staff played a negative role in the sustainability of interventions, emphasizing the need
19
20 for all levels of health professionals to be informed and well-versed in the protocols, with emphasis on
21
22 passing on the information to new healthcare workers in order to continue best practice.⁽¹¹⁾ An
23
24 important gap in current work is the need to affect discharge practices through improved policy and
25
26 guidelines at both national and hospital levels. Every focus group or individual interviewee spoke to the
27
28 importance of guidelines for practice. Improvement in this regard can thus provide the foundation for
29
30 positive change in the post-discharge care of children.

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33 Participants continually emphasized the importance of discharge planning for children throughout the
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35 interviews, expressing unity and motivation to implement process changes. An Iranian study found that
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37 a breakdown in communication between the healthcare team, patients, and families contributed to
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39 parents’ decisions to discharge their children against medical advice, a potential contributor to post-
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41 discharge mortality.⁽¹²⁾ Empowering families, developing a trusting relationship with the healthcare
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43 team, and developing a plan for discharge at the time of admission were considered strategies towards
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45 improving health outcomes and compliance with medical care.⁽¹²⁾

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48 This qualitative exploratory study, designed to describe and provide a basis for further more conclusive
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50 research, is subject to several limitations. First, this study was conducted across seven hospitals in
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3 Uganda, both private not-for-profit and government. While this perspective added substantial
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5 geographical and cultural balance, this study does not capture all regions, and thus may be biased
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7 towards the regions and cultures in which the study was conducted. As well, there may be a lack of
8
9 transferability of findings to other countries or even other levels of health facilities. Related to this, four
10
11 of the seven hospitals have been study sites for post-discharge epidemiology research, although none
12
13 had been involved in any interventional studies involving discharge care. Although no hospital staff were
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15 involved in this research, an increased awareness of the perceived importance of discharge outcomes
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17 may have influenced the generalizability of the perspectives of these participants. Second, a difficulty in
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19 recruiting health care providers as evidenced by the, at times, small focus group sizes or inability to
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21 reach hospital administration for an interview, was offset by the many focus groups and large regional
22
23 representation. Third, although length of interviews and focus groups varied, duration of encounters
24
25 was not determined by the facilitator; thus, interactions were terminated on the basis of participants
26
27 having nothing further to identify or contribute. Finally, this study may be subject to bias due to the fact
28
29 that investigators conducting the interviews and analysis have been involved in past post-discharge
30
31 mortality research. Thus, preconceived notions about barriers, facilitators, and ideas of change may
32
33 have influenced the results. However, this bias may also be beneficial in terms of connecting prior
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35 research findings to the perspectives of the stakeholders being interviewed, thus ultimately benefiting
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37 the development of effective solutions.
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44 Conclusion

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49 Understanding the burden of post-discharge mortality in LMICs through the context of the discharge
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51 process has been a critical gap in the development of effective solutions to improve post-discharge
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53 outcomes. The importance of post-discharge mortality is highlighted through the improved
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55 understanding of current discharge practices and the exploration of barriers, facilitators, and solutions
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3 from the perspective of Ugandan health professionals. The current discharge procedures are largely
4 based on hospital-specific protocol or clinician opinion, and not standardized guidelines. Barriers to
5 discharge are faced by facilities, healthcare staff, and families, and include economic costs, traditional or
6 cultural practices, and a lack of human and physical resources. Teamwork and motivation were
7 identified as critical facilitators required for change. We identified a need for a standardized national
8 policy coupled with appropriate community referral and follow-up and education as essential to
9 improving outcomes for children. This work can serve to facilitate the development of sustainable and
10 effective interventions to improve post-discharge outcomes in Uganda and other similar LMIC settings.
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22 List of Abbreviations

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27 FG: Focus Group

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29 LMIC: Low-and middle-income country
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32 Consent for publication

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36 Consent was obtained from participants for publication of data in signed consent forms.
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39 Availability of data and material

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43 The datasets analysed during the current study are available from the corresponding author on
44 reasonable request. A sample of the data generated or analysed during this study are included in this
45 published article [and its supplementary information files]. Some datasets generated and/or analysed
46 during the current study are not publicly available due to participant confidentiality but are available
47 from the corresponding author on reasonable request.
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Authors' contributions

Brooklyn Nemetchek, MN – carried out data analysis and interpretation, drafted the initial manuscript, critically reviewed and revised the manuscript, approved the final manuscript as submitted, and agrees to be accountable for all aspects of the work.

Asif Khowaja, PhD – contributed to data analysis, interpretation, and drafting of initial manuscript, critically reviewed and revised the manuscript, approved the final manuscript as submitted, and agrees to be accountable for all aspects of the work.

Anthony Kavuma, MBChB – carried out data acquisition, contributed to data interpretation, critically reviewed and revised the manuscript, approved the final manuscript as submitted, and agrees to be accountable for all aspects of the work.

Olive Kabajaasi, MSoc – carried out data acquisition, contributed to data interpretation, critically reviewed and revised the manuscript, approved the final manuscript as submitted, and agrees to be accountable for all aspects of the work.

Alex Olirus Owilli, BSN – contributed to study design and data interpretation, critically reviewed and revised the manuscript, approved the final manuscript as submitted, and agrees to be accountable for all aspects of the work.

J Mark Ansermino, MBBCh, MMed – contributed to data interpretation, critically reviewed and revised the manuscript, approved the final manuscript as submitted, and agrees to be accountable for all aspects of the work.

Susan Fowler-Kerry, PhD – contributed to data interpretation, critically reviewed and revised the manuscript, approved the final manuscript as submitted, and agrees to be accountable for all aspects of the work.

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3 **Shevin Jacob, MD, MPH** – contributed to data interpretation, critically reviewed and revised the
4 manuscript, approved the final manuscript as submitted, and agrees to be accountable for all aspects of
5 the work.
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9
10 **Nathan Kenya-Mugisha, MBChB, MMed** – contributed to study design and data interpretation, critically
11 reviewed and revised the manuscript, approved the final manuscript as submitted, and agrees to be
12 accountable for all aspects of the work.
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16
17 **Jerome Kabakyenga, MBChB, MPH, PhD**—contributed to study design and data interpretation, critically
18 reviewed and revised the manuscript, approved the final manuscript as submitted, and agrees to be
19 accountable for all aspects of the work.
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22

23
24 **Matthew O. Wiens, Pharm D, PhD** – contributed to study conceptualization and design, coordinated
25 and supervised the project, contributed to data interpretation and drafting of initial manuscript,
26 critically reviewed and revised the manuscript and approved the final manuscript as submitted, and
27 agrees to be accountable for all aspects of the work.
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Additional Files

Additional file 1

File format: Microsoft Word document (.docx)

Title: Appendix A

Description: Nursing focus group interview guide, clinician focus group interview guide, and administration individual interview guide.

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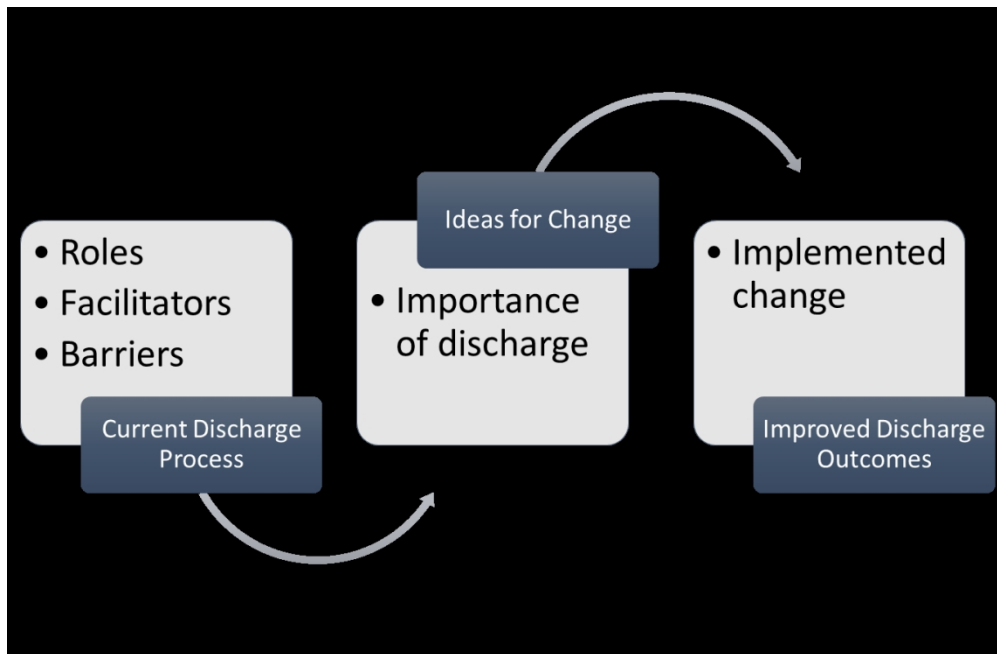


Figure 1

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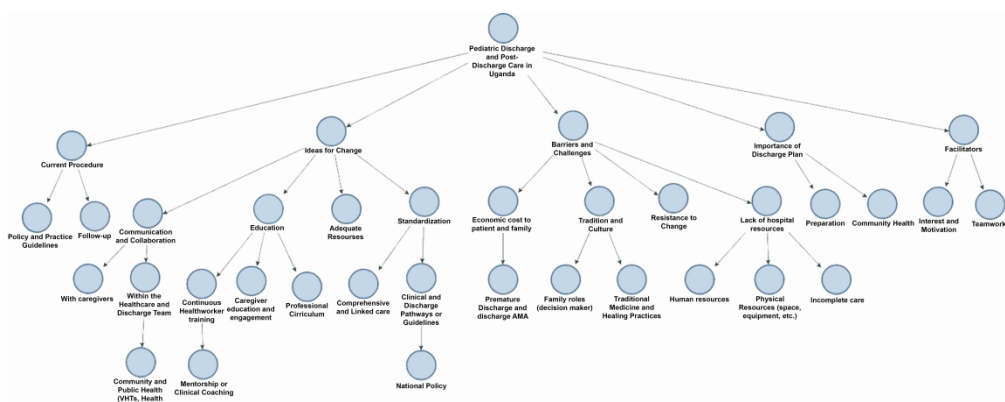


Figure 2

600x238mm (300 x 300 DPI)

Nurse Focus Groups

Interview Date:

Participant Code:

Participant demographics:

Age group: *Please indicate sex below your age range*

Age group	18-25	26-33	34-41	42-49	≥ 50
Sex: M/F					

Education attainment: *Please indicate work history below your profession category*

Profession/discipline	Certificate	Diploma	Undergraduate	Masters	Others
Total years in practice					
Duration of practice in the current hospital					

Discharge process focus group guide

- 1) How do you begin your day in the hospital ward?
 - a) Priority list, handover reports, chart review, review of discharges, and patient follow-up.
- 2) Walk me through the actual process of discharging a child treated for infections from your ward? (Pay attention to when the discharge process is initiated and by whom, planning discharge, teams involved, communication, actual discharge, and follow-up)
 - a) Can you describe to me a little more about the things (special/priorities) that you pay attention to, when effecting discharge?
 - b) Can you explain to me the factors that influence these considerations?
 - c) Are there any follow-up strategies for children discharged? If any, how its done, how often, and by who?
- 3) How long does the discharge process for a child treated for infections take?
 - a) Is the time uniform for every child? Clarify to us what determines the variation?
- 4) Can you describe the roles you assume/play during discharge?
 - a) Explain your role in assessment for readiness of the child for discharge? Describe what happens if you or the mother/caregiver doesn't think the child is well enough to go home? If the doctor says "go discharge that child", can you choose to wait another day due to your judgement? If possible can you give me a scenario?
- 5) Why do you think discharge planning is important? If any,
- 6) Describe to us the challenges you encounter when implementing discharges?
 - a) How have these challenges affected the discharge process?
 - b) Explain to us what you think can be done to improve this?
- 7) Describe the best way to organize a discharge team within this hospital?
- 8) In your opinion, describe the challenges you think about, if your hospital were to introduce a new discharge protocol? Explain what makes it easier for you when there is a new protocol?
- 9) If you were in charge, how would you develop a discharge plan for paediatric inpatients in this hospital?

Physician/Clinical Officer Focus Groups

Interview Date:

Participant Code:

Participant demographics

Age group: *Please indicate sex below your age range*

Age group	18-25	26-33	34-41	42-49	≥50
Sex M/F					

Education attainment: *Please indicate work history below your profession category*

Profession/discipline	Intern	MBChB	MMED	MSc/MPH	PhD
Total years in practice					
Duration (months of practice in the current hospital)					

Focus group discussion guide

- 1) How do you begin your day in the hospital ward?
 - a) Priority list, handover reports, chart review, review of discharges, and patient follow-up.
- 2) Describe to us what processes you consider when discharging a child treated for sepsis?(Pay attention to when the discharge process is initiated and by whom? Planning discharge, teams involved, communication, discharge, and follow-up)
 - a) When does the discharge process begin?
 - b) Explain the priorities you consider when thinking of discharge a child treated for sepsis?
 - c) Follow-up strategies? How it's done, how often, and by who?
- 3) Describe to us the challenges that you face when considering discharge?
 - a) How do you think these challenges affected the children you discharge from the hospital?
 - b) Describe what you think can be done to improve this process?
- 4) Can you describe what roles you assume/play during the discharge process?
 - a) Can you describe to me a little more about how your current roles/activities in the process of discharge have been helpful to your patients?
 - b) Is the decision to discharge a child, solely made by you-the Doctor? Describe what happens if a member of the team on the ward or the mother/caregiver doesn't think the child is well enough to go home?
 - c) Can you explain to us what you think was not right?
 - d) Describe to us the changes you would like to see in the current discharge process?
- 5) Describe to us the best way to organize a discharge team at this hospital?
- 6) How do you see a discharge team function in the hospital setting?
- 7) In your opinion, explain the challenges or facilitators you think about, if your hospital were to introduce a new paediatric discharge protocol?
- 8) If you were in charge, how would you develop a discharge plan for paediatric inpatients in this hospital?

Hospital Administrator In-depth Interviews

Interview Date:

Participant Code:

Participant demographics

Age group: *Please indicate sex below your age range*

Age group	18-25	26-33	34-41	42-49	≥50
Sex M/F					

Education attainment: *Please indicate work history below your profession category*

Profession/Discipline	Undergraduate	MBChB	MMED	MSc/MPH	PhD
Years as administrator					
Years in current position					

In-depth interview guide

- 1) Describe some of the existing policies/guidelines regarding discharge practices in the paediatric unit, for children treated for infections.
- 2) Explain the things regarding discharge guidelines for children treated for infections, that you would like to see being implemented and are not currently in place?
 - a) What are some of the reasons why you want to see them?
- 3) What are some of the reasons to why they are not being done? (Pay attention to human resources, financing strategy, policies)
- 4) Why do you think it is important to plan discharges for children treated for sepsis?
- 5) Describe what you think is required to implement a paediatric discharge protocol in your hospital?
- 6) Describe the current strengths of your hospital in implementing the discharge process?
- 7) Describe the changes in the current discharge practices you assume need to be made to implement a new paediatric discharge protocol?
- 8) Describe the probable challenges you foresee with implementing a new paediatric discharge protocol?
- 9) How can these challenges be addressed?
- 10) If you were in charge, how would you develop a discharge plan for paediatric inpatients in this hospital?

Standards for Reporting Qualitative Research (SRQR)

O'Brien B.C., Harris, I.B., Beckman, T.J., Reed, D.A., & Cook, D.A. (2014). Standards for reporting qualitative research: a synthesis of recommendations. *Academic Medicine*, 89(9), 1245-1251.

No.	Topic	Item	Page no.
	Title and abstract		
S1	Title	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes objective, methods, results, and conclusions	3,4
	Introduction		
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	6
S4	Purpose or research question	Purpose of the study and specific objectives or questions	6
	Methods		
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., positivist, constructivist/interpretivist) is also recommended	7
S6	Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, or transferability	9,1
S7	Context	Setting/site and salient contextual factors; rationale ^a	7
S8	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale ^a	8
S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	9
S10	Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale ^a	8,9

S11	Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	8,9 (reference to additional file)
S12	Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	8,10,11
S13	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	9
S14	Data analysis	Process by which inferences, themes, etc., were identified and developed, including researchers involved in data analysis; usually references a specific paradigm or approach; rationale ^a	9 (with reference to figure 1 and 2)
S15	Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale ^a	8,9
Results/Findings			
S16	Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	10-21
S17	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	10-21
Discussion			
S18	Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	21-24
S19	Limitations	Trustworthiness and limitations of findings	23,24
Other			
S20	Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	5
S21	Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting	5

^aThe rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.