CARING *for* CAREGIVERS

Results of a Formative Study of Bedside Caregiving in Arthur Davison Children's Hospital

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STUDY BACKGROUND

Arthur Davison Children's Hospital (ADCH) provides cost-effective healthcare to children aged between 0 and 14 years. Bedsiders are critical to care in hospitals and other health care settings in Zambia. These bedsiders often face challenges that can affect the health outcomes of the patient and the bedsider, as well as the household (Mutanekelwa and Chileshe, 2020; Chileshe, Bunkley, and Hunleth, 2022). Efforts exist to assist bedsiders in hospitals and other health care settings in Zambia, including in ADCH. Such efforts include, but are not limited to, mothers' shelters, other hospitals, and clinics serving remote locations. At present, efforts to support bedsiders are often limited in scope, rely on the capacity of individuals, and are constrained by funding. Such efforts may provide important support to bedsiders. However, there are limited studies on the effectiveness of such support due to their scope and scale. Alternatively, studied interventions that have been shown effective in other contexts or with caregivers of adult patients may not reflect the needs of healthcare professionals and caregivers of pediatric patients at ADCH and in Zambia.

OUR OBJECTIVES

In this study, we carried out formative research in ADCH to understand the roles bedsiders played in the hospital and their supportive care needs. Bedsiders exist in hospitals and health care settings throughout Zambia. Thus, the issues indicated in this report apply and will be useful to hospitals and health care settings throughout Zambia. Our objectives are as follows:

- Broadly describe the situation of bedsiding in the hospital from the perspectives of healthcare professionals and bedsiders
- Examine in-depth bedsiders' personal narratives that shape their experiences in the hospital
- Identify bedsiders' needs as well as strong practices, areas for growth, and recommendations for ADCH and other facilities seeking to support bedsiders

PARTICIPANTS

To accomplish these objectives, we interviewed healthcare professionals (n=44) and bedsiders (n=30) at ADCH, and conducted site visits.

All names used in this pamphlet are pseudonyms to protect anonymity.

FUNDING PARTNERS

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EVALUATION METHODS

	Part 1	Part 2
Study Design	Qualitative, semi-structured interview	Qualitative, narrative interview; observational, in mother's shelter and key sites in hospital
Participants	44 health professionals (doctors, nurses, other roles)	30 bedsiders currently in hospital for ≥ five days
Data Collection	Telephone, WhatsApp, or Zoom interviews	Narrative interviews carried out in private rooms at the hospital (following COVID-19 safety protocols)
Data Analysis	Content analysis using a priori categories and emerging codes.	Content analysis using a priori categories and emergent codes. Case summaries reviewed using constant comparison.

Demographics of Participants

Healthcare Professionals Sociodemographics (n=44)			
Gender	Men	11	25%
	Women	33	75%
Age	*Ages 25-54; Mean 32.92 (SD ± 8.25); Median 29.5*		
Profession	Doctor	15	34%
	Nurse	24	55%
	Other	5	11%
Years in Practice	*0.17-25 years; Mean=6 (SD ± 6.38); Median 6.00*		
Years at ADCH	*0.17-25 years; Mean=4.79 (SD ±6.35); Median 1.5*		

Age was not asked for 2 participants; Profession was not asked for 1 participant; Years in practice was not asked for 2 participants; Years at ADCH was not asked for 1 participant.

Bedsiders Sociodemographics (n=30)			
Gender	Men	3	10%
	Women	27	90%
Marital Status of Bedsider	Married	21	70%
	Single*	9	30%
Age	*Ages 20-60; Mean 36.3(SD ± 10.40); Median 34*		
Relation to Child	Mother**	17	57%
	Other***	13	43%
Family in Ndola	Yes	23	77%
	No	7	23%
Age of Child Patient	Less than 6 months	8	26%
	6 months- 1 year	0	0%
	1 year – 5 years	7	23%
	6 years and above	16	52%
Gender of Child	Boy	15	48%
	Girl	16	52%
Time in Hospital	less than 1 week	6	20%
	1 week - 2 weeks	16	53.33%
	2 weeks 1 day- 3 weeks	1	3.33%
	3 weeks 1 day - 4 weeks	2	6.67%
	4 weeks 1 day - 8 weeks	3	10%
	8 weeks 1 day or more	2	6.67%

Note: We interviewed 30 bedsiders caring for 31 children (one set of twins). One participant was not asked if they have family in Ndola.
** Single includes participants who are separated, divorced, or widowed*
*** Includes stepmothers*
**** Other includes grandmother, aunt, or father*

BEDSIDING ROLES

"That's the beauty of having a bedsider. Because we don't have the capacity to deal with the patients the whole time as health workers" Dr. Siwa – Health worker 006

"We are understaffed, so you can't really check on each and every patient, so the caregiver is like a third eye on the ward. If anything goes wrong, they can inform you as soon as possible. And because of that, lives can be saved, or interventions can become early" Dr. Kapamba – Health worker 012

"We rely on mothers... if there is development of new symptoms, they're able to take note, and with that you'll be guided whereas to change the mode of treatment or maintain, to understand" Dr. Zimba – Health worker 005

Nursing and comforting patients
Bedsiders calmed children and assisted the nurses with feeding, cleaning, and giving medication.

Communicating with healthcare professionals about patient needs
Bedsiders alerted healthcare professionals if there was a change in the patient's condition. Some challenges were language barriers, disagreement about diagnosis, and bedsiders feeling disrespected.

Coordinating patient care
Bedsiders ran medical errands in and out of the hospital. This supported clinical care but could be challenging when they were also expected to stay with the patient throughout their time at the hospital.

Table 3: Bedsider Roles, Benefits, and Challenges

Role	Activities or tasks listed by healthcare professionals		Benefits	Challenges
Comfort and Nursing Patient	• Taking child to the hospital • Bathing patient • Feeding patient • Brushing patient's teeth • Changing patient's clothes • Taking patient to toilet/managing bedpan • Changing diapers • Bandage/wound care • Washing bedding/clothing • Monitoring injuries and illness • Trying supplementary healing methods including specialty foods and drinks • Purchasing food, medicine, tests, detergent, etc. • Avoid shouting/getting upset	• Sitting with patient: Comforting, encouraging, keeping their spirits up • Praying with patient • Playing with patient • Massaging patient • Turning patient to different positions • Lifting and holding • Cooing to sleep • Explaning the illness and treatment to patient • Asking what the patient needs and fulfilling their requests • Monitoring body temperature • Taking patient out for fresh air	• Someone is always with the patient • Healthcare workers felt better knowing someone was with the patient given the low provider to patient ratio	• High volume of people in the ward could cause overcrowding and disrupt workflows • Bedsiders could add to the stress experienced by healthcare workers
Communicating	• Communicating patient medical history • Alerting staff to changes in condition • Reminding staff about medicine and medication times • Being present when medicine is given	• Listening to and observing doctors; asking questions • Learning from hospital staff on how to give care • Assessing the care received	• Alerting staff to changes in patient health status • Communicating with people outside the hospital for assistance	• Language barriers • Fear of retaliation: emotional/physical outbursts/violence • Bedsiders don't always understand the patient's condition and either question or disagree with healthcare workers' decisions
Coordinating Patient Care	• Buying medicine and medical equipment • Running labs • Getting lab results	• Giving blood (at outside lab) • Following up on referrals	• Ability to get things (blood, meds) that are not available in hospital	• Not having money • Wanting to leave before patient is healed to get back to work • Other children

CASE STUDY 1: STIGMATIZED CONDITIONS

KEY POINTS

- Stigmatized conditions isolated bedsiders from social networks.
- Bedsiders experienced fear around patient death and surgeries.
- No bedsider swapping led to greater bedsider burnout.
- Divorced or separated bedsiders faced increased financial, logistical, and emotional challenges.
- Bedsiders managed emotions to remain positive for patients.
- Comprehensive education about conditions helped encourage bedsiders.

"You know when a person is facing problems, people always laugh. When the baby's head started growing, there were people who started laughing at me and passing comments like, 'look at the kind of child she has given birth to.' Some would say, 'why has she given birth to such a child, why does the child have a big head?' They said maybe I did something, yes, some even called me all sort of names. I tell you."

Prisca
24-year-old mother

Prisca was a 24-year-old mother who brought her three-month-old son, Richard, to ADCH. Richard was diagnosed with hydrocephalus at birth. He and Prisca spent the first month of his life in the hospital. After being discharged, Richard's head began swelling, and he had a fever. Richard's swelling head became the subject of gossip amongst Prisca's friends and church community. Rather than supporting her and her son, people seemed to blame Prisca for this stigmatized condition. Prisca shared with us: *"You know when a person is facing problems, people always laugh. When the baby's head started growing, there were people who started laughing at me and passing comments like, 'look at the kind of child she has given birth to.' Some would say, 'why has she given birth to such a child, why does the child have a big head?' They said maybe I did something, yes, some even called me all sort of names. I tell you."* Because of this gossip, Prisca stopped singing in her praise group or going to services.

Prisca returned to the hospital because the doctors said Richard needed to have a shunt put into his head to relieve the swelling. Prisca was concerned about the surgery. Prisca said, *"Some said when they take the child in for theatre, the child might die. They were telling me that if the child goes for theatre, they would die, and it made me scared."* She became very frightened but still chose to move forward with the procedure. From his birth until our interview (3 months), Richard had spent his entire life in and out of the hospital, and Prisca had remained by his side despite having another child at home.

It was difficult for Prisca to manage the day-to-day care of Richard while in the hospital because Prisca could not swap places with another bedsider due to hospital COVID-19 restriction. Prisca managed all communications with hospital staff and alerted them to any changes in Richard's condition. Prisca faced the added burden of the responsibility to acquire needed medicines outside of the hospital while not having the financial stability of someone in the household working. Even though Prisca was married, she was separated from her husband who refused to provide support. Her brother and other family had other responsibilities to attend to that made them not fully available to support her. Prisca worked hard throughout her hospital stay to make sure she was managing her emotions for Richard, sharing *"[Bedsiders] are not supposed to be sorrowful, but should be strong because they are the ones nursing the patient."* At the time of the interview, Prisca's knowledge about the disease, gained from nurses and doctors, gave her courage to rejoin her praise group.

CASE STUDY 2: TROUBLES AT HOME

Natasha was 22 years old when we interviewed her. She travelled over 5 hours to Ndola to bring her sick son, Angel, to Arthur Davison Children's Hospital for treatment. Angel was 7 years old and had been at Arthur Davison Children's Hospital for 2 months for what the doctors described as kidney damage. Natasha and her son waited several weeks for a catheter. The catheter worked for a while, reducing the swelling in his legs, but after about a week it stopped working and the swelling returned. The hospital did not have another catheter that might be used to help with the swelling. The hospital tried to decide whether or not Natasha and her son would need to seek treatment elsewhere.

Natasha began to feel despair; the other bedsiders' children were all improving while her own son's condition was worsening. She told Dr. Asante (interviewer) that she just had to remain strong. She had to stay strong for her son. When Dr. Asante asked Natasha what challenges she was facing, Natasha replied, *"Even if it's at home, the way we live isn't good. This same stepfather that we live with uses harsh words over Angel. So, sometimes my heart really hurts."* Dr. Asante then asked: *"Could you tell me the latest incidence in which he used harsh words? Give me an example of what he said."* Natasha explained to Dr. Asante that she had returned home from a funeral and found her son, Angel, crying. She asked what was wrong, and Angel told her that the stepfather had yelled at him, telling him to go outside. Natasha confronted her husband, and he told her *"I don't want this child, take him to your Grandmother."* They disagreed on this with Natasha saying she was his mother, and he should remain with her. After this incident, Angel's condition worsened, and two days later, she took him to the local clinic to seek care. Angel's blood pressure continued to rise while at the local clinic, something Natasha believed to be a result of her husband yelling at him. Angel began to question if this man was his biological father, something he had not been told, but he surmised from how harshly he was treated.

KEY POINTS

- Hard home life makes managing illness more difficult for bedsiders and patients. Sometimes, the hospital is a reprieve from the difficulties at home.
- Bedsiders become concerned if their child does not improve while in the hospital. They can also face stigma because of this.
- Bedsiders see how troubles at home affect their children and work hard to manage their emotions for their children.

> *"Even if it's at home, the way we live isn't good. This same stepfather that we live with uses harsh words over Angel. So, sometimes my heart really hurts."*
>
> **Natasha**
> 22-year-old mother

CASE STUDY 3: TRAVELING FROM FAR AWAY

KEY POINTS

- Transferring between clinics is difficult.
- Transportation from remote areas is challenging.
- Being widowed makes it very difficult, financially and emotionally.
- Many bedsiders in positions similar to Chitalu found buying medication very financially difficult. There were often times when bedsiders could not afford medication.

"I think I'm just alone."

Chitalu
47-year-old widow and mother

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Chitalu was a 47-year-old widow. She had initially brought her daughter to her local clinic, about an hour from her home, because the child was having trouble breathing and eating. The local clinic determined Miriam had Down syndrome and had holes in her heart that perhaps could be treated with medication. However, Miriam's breathing issues persisted, and the local clinic referred them to Arthur Davison Children's Hospital. At ADCH, it was determined Miriam would need to go to Lusaka for heart surgery. Chitalu and Miriam were waiting to transfer to Lusaka for the operation and weren't sure when they would be leaving. Work had slowed down in the clinics and hospitals due to COVID-19. Traveling from far away made it difficult for Chitalu to stay in touch with her other children. It also made it difficult for her to access her social support network. Chitalu said, *"I think I'm just alone."* Chitalu became emotional, not knowing if the medication would work, not knowing about the operation in Lusaka, and not fully understanding the issues with her child and whether or not she would get better. Without a husband, she could not afford all the things necessary to treat Miriam. Chitalu said *"I am told to go and buy medication. I'm failing to do so, because how will I buy without money?"* Miriam had had difficulties breathing before, but Chitalu did not always have the money to take her to the local clinic or to ADCH. The recent loss of her husband, needing to travel far distances, having to coordinate childcare for her other children, and the prohibitive costs of healthcare all made seeking treatment for her daughter Miriam very difficult.

CASE STUDY 4: BEING A MALE CAREGIVER

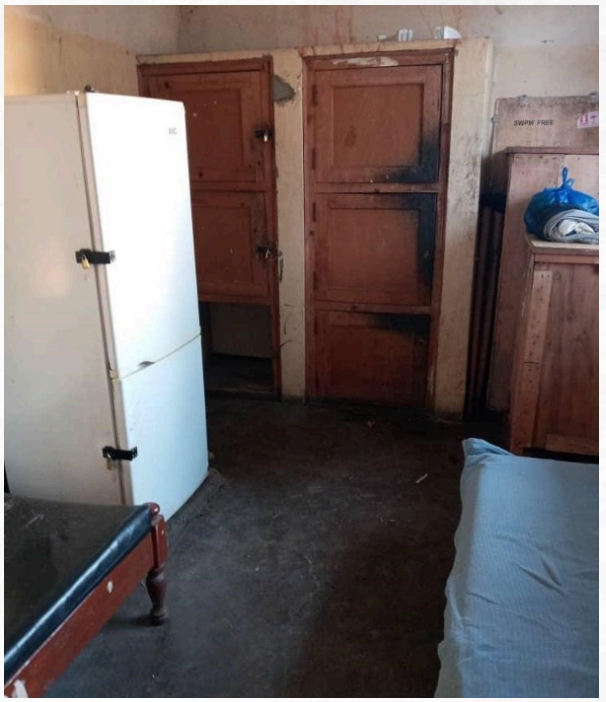
Thomas was 35 years old and had brought his 10-year-old son, Kelvin, into the hospital because his entire body had swollen up. Initially, Thomas had taken Kelvin to their local clinic where he was given a variety of medications and injections. Nothing seemed to work or help the condition. Kelvin began vomiting and having what Thomas described as "fits." The clinic arranged for an ambulance to take Thomas and Kelvin directly to the emergency room at Arthur Davison Children's Hospital in Ndola, about 9 hours away from the local clinic where they were seeking treatment. Despite having been at the hospital in Ndola for 2 weeks, Kelvin's condition had not changed and there was not a satisfactory diagnosis, save for trouble with the kidneys and blood pressure. When asked about the biggest challenge of being a bedsider, Thomas responded: "*You just know when it comes to giving care, it's different, [and] you would find that you are giving care. If it's a young person that cannot walk or do anything, it is very difficult, because at any given time, you have to lift him, do this and that, everything is on you, cleaning up urine is on you, everything he might need is on you, you have to go outside to buy, you go back inside, you're just everywhere, there's no sleep, you can't eat proper food, no, because your heart isn't fully settled.*" Thomas had taken up the role of primary bedsider at his son's bedside in lieu of his wife who had just given birth and was breastfeeding their newborn at home. Like Natasha, he was managing his heart to show strength for his family back home and provide support to his ailing son.

KEY POINTS

- Male caregivers have unique experiences in the hospital.
- Male caregivers are often the head of household for their families. Being in the hospital and unable to work places additional financial strain on the household.
- Male caregivers often served as bedsiders on behalf of their wives when their wives were pregnant, sick, or had died.

"Everything he might need is on you, there's no sleep, you can't eat proper food, no, because your heart isn't fully settled.".

Thomas
35-year-old father



BEDSIDERS

appreciate services and resources at the hospital

Bedsiders acknowledged that healthcare professionals at ADCH were hard working. Bedsiders especially appreciated when healthcare professionals were able to take the time to listen to them, encourage them, and patiently explain the patient's diagnosis and treatment protocol to them.

Those who received medication and treatments through the hospital at no cost identified how much this meant to their child's recovery. Bedsiders who received food as part of their child's portion identified that this enabled them to stay in the hospital.

> *"Well, they are really taking care of the child, they are giving her medicine, they are not getting tired of us, they are cleaning her wounds, when I am lacking, they are giving me money to buy things for the child."* Nkandu – Bedsider 011

> *"What has encouraged me, according to the treatment they are giving the children and also the food, it has encouraged me because I won't have thoughts wondering what I will eat."* Bwalya – Bedsider 023

They especially praised healthcare professionals who were friendly, empathetic, and made kind gestures.

> *"So, she saw and said if 'it's that way, if you want the stairs, we will go together.' That's how I said 'ah, you can go nurse with the elevator, I will use the stairs.' Then she said 'no, that's not how it should be. I'm supposed to be with you, that's how we can with the stairs.' I saw something different because the sisters were being very friendly."* Gertrude – Bedsider 009

Bedsiders appreciated when healthcare professionals attended to their own health problems or needs.

> *"They really help, because there's a time, I got a cough and a flu. I just recovered from it because they had given me some medications"* Prisca – Bedsider 004

The mothers' shelter has beds and places to wash for bedsiders to come and refresh.

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Bedsiders face many challenges, and resources, good communication, kindness, and a focus on bedsider health went a long way to encourage bedsiders during a difficult time. Bedsiders were also understanding of the constraints on healthcare professionals when they saw them working hard and doing their best.

COVID-19

This research was carried out during the first and second waves of COVID-19 in Zambia. This context offered several lessons in terms of our study.

- It showed how over-stretched healthcare professionals and resources were prior to and during the pandemic.
- At certain time points, COVID-19 restrictions created more manageable work environments due to reduced admissions. However, it affected healthcare professionals who were getting sick and because some essential services were suspended to address the pandemic.
- It showed how much bedsiders, their family members, and social networks were doing for the hospital and the patient.

> *"At least we are happy with the services that we are offering them then. At least the ward is manageable, and we are able to complete most of the tasks than before COVID."* Ms. Mabel – Health worker 020

> *"But now we are having adequate space...We actually even work effectively now that [there are fewer] people in the hospital."* Ms. Beatrice – Health worker 031

Key Hospital Changes During 2020 COVID-19 Pandemic

Pre-Pandemic

- No COVID-19 testing prior to admission
- Hygiene and minimizing disease transmission important
- Visitors allowed
- Bedsider exchange happening informally
- Space congested with too many people
- High nurse/doctor: patient/bedsider ratio

VS

Pandemic

- COVID-19 testing prior to admission with quarantine if positive
- Increased attention to hygiene and educating bedsiders – hand washing, social distancing, mask wearing
- Increased need for personal protective equipment (masks, gloves, gowns)
- Visitors not allowed
- Bedsiders could not swap without permission
- More manageable space
- More manageable nurse/doctor: patient/bedsider ratio

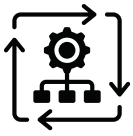
Implications of COVID-19 Restrictions and Resulting Improvisation by Bedsiders, Hospital Staff, and Social Networks

COVID-19 Policy Restriction	Implication	Improvisation (Some present before COVID-19 but may have been altered or disrupted)
Material Impacts		
Restricted visitation	• Bedsiders had limited physical access to social networks • Social networks had reduced capacity to provide material support to bedsiders, including food, medicine, and money • Bedsiders were not able to provide certain necessities to care for their child and themselves	• Social Network to Bedsider: Friends and family passed material goods and money at the gate • Social Network to Bedsider: Friends and family sent money through digital money platforms • Bedsider to Bedsider: Shared food and prayers with each other, particularly when a bedsider could not obtain necessities through their social network • Hospital Staff to Bedsider: Nurses advocated for bedsiders without family or friends to provide their material needs through connecting them with the social worker and kitchen staff
Restricted bedsider exchange	• Bedsiders lost income generating opportunities due to inability to leave the hospital • Bedsiders forwent other caring needs, particularly in cases where the bedsider had other children in their care	• Social Network to Bedsider: Friends and relatives sometimes helped with bedsiders' businesses in their absence • Bedsider to Bedsider: Other caregivers stepped in to care for other children left at home • Social Network to Bedsider: Older children took care of the home, and the bedsider made sure to leave enough money for the children to get what they needed.
Physical Impacts		
Restricted visitation	• Visitor restrictions resulted in limited physical interactions with patients and bedsiders • Bedsiders and patients received less emotional encouragement from family members • Many bedsiders reported feeling alone and isolated during their child's hospitalization	• Hospital Staff to Bedsider: Health workers stepped in to provide emotional support to bedsiders, especially when they were the only support the bedsider had • Social Network to Bedsider: Family and friends provided emotional support through phone calls when physical visitation was limited • Bedsider to Bedsider: Bedsiders encouraged each other and prayed together
Restricted bedsider exchange	• Bedsiders experienced mental distress as a result of providing around the clock care without breaks from the bedsiding role • Bedsiders felt solely responsible for all caregiving and for the health outcome of the child	• Bedsiders relied on their faith to get them through emotionally challenging times

HEALTHCARE PROFESSIONALS

suggestions to improve conditions for bedsiders

Infrastructure



- Making medical insurance accessible
- Increasing hospital capacity
- Expanding mothers' and fathers' shelters

Resources

- Hospital staffing
- Equipment
- Increasing testing capacity
- Addressing drug shortages
- Providing for bedsiders

Bedsider-Healthcare Provider Communication

- Ensuring the bedsider understands the situation
- Reassuring patients and bedsiders
- Providing psychological and emotional support
- Encouraging bedsiders could help them remain in the hospital for the full duration

Broader Prevention within the Community

- Increasing focus on preventative health
- Strengthening public health programming

"At the end of the day, medicine is supposed to be holistic care. And I think a bedsider can only take care of a patient if they are well rested, if they are okay. They need adequate rest... They need to be okay for them to be able to provide that kind of care for the child. We don't have the luxury of having enough nurses to be by the bedside all the time. So, the bedsiders are kind of like the nurses. They're, like, nursing these patients as well. And such a program would definitely be helpful because if the bedsider is, you know, top-notch, then I think that would greatly influence the patient's healing process." Dr. Mukupta - Health worker 10

"I've had cases where I've taken time to offer a lot of counseling, and especially the bedsider. One of the cases I had taken that time, or two, I'll give the examples. One case was a child with sickle cell anemia. The other one was a child with the diabetes type 1. I had taken time to explain to them triggers for a crisis, how to avoid such, and the benefit of having the child on pharmacology and all those other measures that we do. The bedsider understood the importance of such measures, and doing follow-ups, I've seen a lot of improvement in the child, and I've seen a lot of positive outcomes besides. Even in the DM child that I had taken time to explain how to administer the insulin, hypoglycemic awareness, and all other things to manage the sugars. The child has been improving quite dramatically, and we're having less complications of them. So that was a good sign that information to bedsiders is key in managing our patients." Dr Lesa - Health worker 08

"They are like nurses themselves. Most of the procedures become assisted because they are there. For example, we monitor them giving medication, a drug to a patient, for example, administering oral drugs. We will calculate, and we'll give it to the mother, and observe how she's giving. On the assisted baths, for example, we'll monitor them and see how they are doing a bath on a child, so some procedures have become assisted instead of fully us doing the procedure." Ms. Christine – Health worker 41

Figure 1. Social Support Model

The importance of the model is 3-fold.
First, it extends a focus on support beyond the patient-caregiver dyad or the patient-caregiver-provider triad. **Second** and related, the model situates bedsider actions and health within a constellation of relations both in and outside of the hospital. This is critical so as not to blame bedsiders. **Third**, the model shows how precarity can happen when one group of actors is not accessible or is overwhelmed. COVID-19 restrictions limited collective care in the hospital because of the protocols enacted to prevent disease spread.

This model brings interdependence into plain view. Such interdependence is not just between actor groups, but also within groups. Noticing where support is limited can guide interventionists to where structural support or other action is most needed.

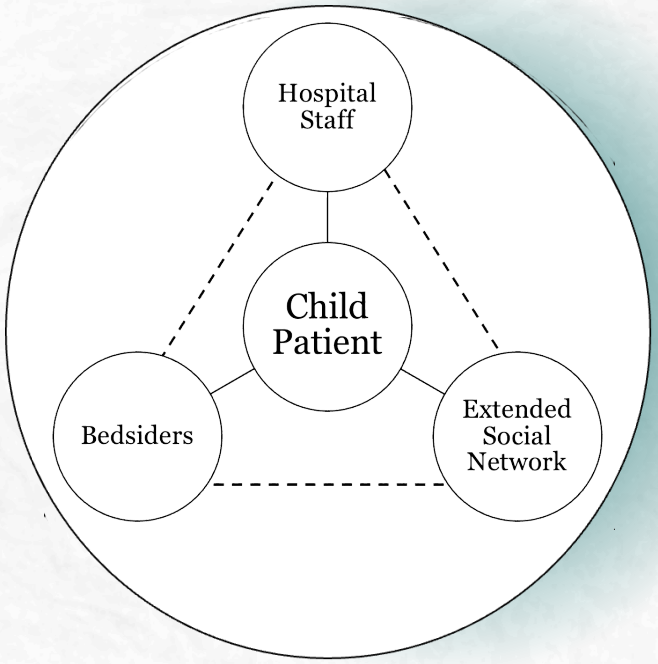


Figure 2. Heterogeneity of Bedsiding in a Pediatric Hospital in Zambia

We identify the multiple and multi-level factors that were affecting the bedsiding experience at ADCH. Any bedsider intervention must acknowledge the heterogeneity in the experience of bedsiding and tailor support accordingly (as opposed to a one-size-fits-all approach). This figure also makes evident the social context, factors, and relationships to assess when identifying supportive care needs.

1	2	3	4
BEDSIDER	**CHILD RECEIVING CARE**	**BEDSIDING CHARACTERISTICS**	**BEDSIDING CONTEXT**
age, gender, marital status, socio-economic status, work and employment, physical and mental health, education, language, cultural background, religion/spirituality	age, gender, relation to bedsider, disease/condition, functional/cognitive status, abilities and strengths, health care needs, relationships in hospital	length of bedsiding, bedsider experience, communication/ advocacy skills, reasons/motivation for bedsiding, relationship quality (with child patient, family, nurses, doctors, staff, other bedsiders), strength/proximity of social network, other family and household obligations	living situation, setting, financial resources, community resources, hospital infrastructure and resources, season, government health regulations

Figure 3. Socioecological Model of Identified Practices & Needs to Improve Conditions for Bedsiders

The below model disaggregates the best practices and suggestions identified during our study by the healthcare professionals and bedsiders. We focus at the societal, community, hospital, and bedsider levels, showing what is happening already and what could be leveraged to ensure bedsider and child wellbeing.

Societal

- Number and capacity of children's hospitals
- Specialists and social workers
- Hospital staff and clinician pay
- Supply chains
- Health insurance
- Economic and employment opportunities
- Gender equity in health, economic, and educational opportunities

Community

- Primary care services
  - Staffed and resourced
  - Referral support at primary care level (e.g., what to expect at tertiary hospital; resources available)
- Preventative programming and education
- Seasonal preparedness
- Gender equity in health, economic, and educational opportunities

Hospital

- Opportunities for bedsiders to ask questions about treatment or prevention
- Programs to support bedsider psychosocial needs
- Space for bedsiders at the bedside
- Facilities for bedsiders close to the bedside
- Lockers for bedsiders to safely store belongings
- Food and sanitary items for bedsiders
- Pathways to identify/treat bedsider health and social needs

Bedsider

- Bedsider-to-bedsider peer support

*Figure adapted from Young et al.'s (2020) systematic review of caregiver interventions

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RECOMMENDATIONS

for identifying and supporting bedsiders

That all interventions in the hospital attend to the multiple actors who make up support for the patient. In the Social Support Model, we show the interwoven relationships of support between patients, bedsiders, hospital staff, and bedsider social networks.

That interventions consider the heterogeneity among bedsiders that factor into bedsiders' needs and experiences in and outside of the hospital.

That interventions attend to multiple levels of influence. In the Socioecological Model, we have taken suggestions for change given by bedsiders and healthcare professionals and illustrated potential interventions at every level from the individual bedsider and healthcare professional all the way to Zambian national policy.

What suggestions might you have to improve conditions for bedsiders?

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Dr. Mutale Chileshe, 1978-2021

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Arthur Davison Children's Hospital:
To all of the administrators, clinicians, staff, and bedsiders.

CARING *for* CAREGIVERS

Question

Question

Notes and Reflection

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